

HEALTHY CHILDREN FOR A HEALTHY FUTURE – CURRENT STATUS AND EXPECTATIONS



Interview with **Assoc. Prof. MONICA DESIREE DRAGOMIR, MD, PhD**

Primary care physician in hematology and pediatric oncology
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Doctor of medicine – PhD (Oncology)
Head of department, Pediatric oncology

department of the „Prof. Dr. Al. Trestioreanu“ Oncological Institute, Bucharest (research and medical activity in the institute since 1989)

Associate Professor, "Carol Davila" University of Medicine and Pharmacy, Bucharest (teaching activity since 1991)

Member of medical scientific societies

National societies

- SROHP – Romanian Society of Pediatric Onco-Hematology – founding member
- Romanian Society of Pediatrics
- Romanian National Society of Medical Oncology
- Romanian Society of Neurooncology – founding member

International societies

- ESMO – The European Society for Medical Oncology
- SIOP – International Society of Pediatric Oncology
- SIOPE – International Society of Pediatric Oncology Europe
- ASCO – American Society of Clinical Oncology
- MASCC – Multinational Association for Supportive care in Cancer
- EANO – European Association on Neuro-Oncology

At present

President of SROHP (Romanian Society of Pediatric Onco-Hematology)

President of the Coalition for the Cause of Childhood with Cancer (CCCC)

Chair of the Pediatric Hematology-Oncology Commission of the Ministry of Health

Chair of the Committee of experts on national coordinators for the implementation of national curative health programs – Sub-program for active monitoring of specific cancer therapies by PET-CT in children

Representing member of Romania in the SIOPE Clinical Research Council for Pediatric and Adolescent Oncology (SIOPE CRC)

European projects – ongoing

H2020EU PROJECT: PRIMAGE (PRedictive In-silico Multiscale Analytics to support cancer personalized diagnosis and prognosis, Empowered by imaging biomarkers)

BENCHISTA – Understanding why childhood cancer survival varies between countries

PARTNER – Paediatric Rare Tumour European Registry for children and adolescents: VRT (very rare tumours).

Reporter: Dear Mrs. President, you are the founding member of a medical society in a specific field, that of pediatric onco-hematology.

- Why was it necessary to set up this society?

MONICA DESIREE DRAGOMIR: The Romanian Society of Pediatric Onco-hematology (SROHP) was founded in 2001. I am one of the founding members, who were, in fact, all the doctors involved in the network of pediatric onco-hematology at that time. The initiative belonged to Mr. Dr. Sebastian Nicolau, who was also the president of SROHP for a long time. According to the articles of association of our professional society, the aim was "to develop, affirm and deepen the theoretical and practical knowledge of oncopediatrics (child cancer) and hematology". In 2001, there were very few pediatricians and oncologists working in this field. Means of communication with colleagues in other countries were limited by distance. The Internet and online communication were in the beginning in our country. The means of information were limited, so we had to gather the scientific information that everyone obtained (at international congresses and conferences, during the internships in high-performing medical centers) and share it with everyone. It was the beginning of our professional integration into the international community and the implementation in our country of the therapeutic performances that were possible in Western European countries and the United States. The difference in therapeutic resources was significant at that time. Only together could we build a non-existent specialty in our country and practice it to high standards, which were evolving rapidly.

- What were the opportunities and obstacles of the beginning of the road and what were the main stages of development of this society?

MDD: At the beginning, SROHP's activity was limited to the organization of annual scientific conferences, at national and international level. Having a good collaboration with colleagues from Hungary, we organized together specialized conferences: Romanian – Hungarian Pediatric Oncology Meeting, with alternative location Romania – Hungary. In 2019, we have reached the 22nd edition. Subsequently, the conferences had a wide participation at European regional level - Central-Eastern / South-Eastern European Pediatric Onco-Hematology Meeting,

the 14th in 2019. I hope to re-organize them this year. They were the best way to exchange experience, to learn from each other how to implement European standard therapies in our country, which was a challenge for all former socialist countries. These conferences have had mutually beneficial influences for all of us, because we had and still have common problems and difficulties, the solution of which we have learned from each other.

In 2015, SROHP joined SIOPEuropa (European Society for Pediatric Oncology Europe) as a national professional society member of the European National Pediatric Haemato-Oncology Societies (NaPHOS). Thus, the president of the society is a member of the SIOPE Clinical Research Council for Pediatric and Adolescent Oncology (SIOPE CRC), which represents the clinical research community in pediatric oncology in Europe. Since then, 2 pediatric hematology and oncology centers (Bucharest Oncological Institute and Fundeni Institute) have been recognized and accredited as affiliated members of ERN PAED-CAN – European Reference Network for Pediatric Oncology. Currently, pediatric oncology centers in Romania and Romanian specialists, who wanted to get involved, are part of international working groups.

R. In view of your involvement in the management of this company, your professional training, expertise and experience gained, both in the specific field and in health management, we would like to obtain from you an informed opinion on the organization and operation of the pediatrics in Romania.

- What relevant organizational changes do you consider to have taken place over time and have had an impact on the provision of pediatric care in Romania?

MDD: With the taking over of the SROHP leadership, 8 years ago, but also as a member or chairman of the Pediatric Onco-hematology Commission of the Ministry of Health, we have repeatedly made decisions to the decision-makers to solve fundamental problems in the functioning of this important sector of health care. pediatric. It was difficult due to the political situation that involved frequent changes in the management team of the Ministry of Health and National Health Insurance House (CNAS). Regardless of the political color, we had empathy and support from everyone, but there was not enough time to put our demands into practice. It took tenacity, perseverance and consistency to get some legislative changes and rules, but they radically changed the existence and prospects of pediatric hematology and oncology care in Romania. One of the most important achievements was the establishment of the specialty of hematology and pediatric oncology in October 2016. In Romania, there was no way to specialize in this field for over 15 years. Also in 2016, our specialty was included, along with oncology and hematology, in the categories that benefit from salary increases of 35-50%, which is extremely important for the loyalty of medical staff (in permanent deficit), given the difficulty, the responsibility and the psychological impact that this field of medical activity implies. Thus, we hope to attract a larger number of young doctors in this specialty. Unfortunately, their number is much smaller than the need for spe-

cialists in the country. Of those who initially opted for this residency, half give up along the way.

From the point of view of specialized medical practice, we obtained from CNAS the formation of medical decision commissions with a program adapted to pediatric needs (approvals for PET/CT evaluations), as well as genetic diagnosis programs in leukemias and solid tumors. Another legislative change that we have achieved in favor of our patients, with the support of the Ministry of Labor and Social Protection, has been to change the criteria for inclusion in categories of disability, so that both patients and survivors of children with cancer benefit from the support. financial and social situation resulting from the classification in the category of degree I disability.

- What is the purpose and what is the current mission of the company? What are your prospects for this company?

MDD: Currently, the company's mission is to implement in Romania all European standards of good medical practice and research in the field of hematology and pediatric oncology. To this end, our proposals for the recently launched National Cancer Plan 2022-2026 have 5 major objectives: multidisciplinary integrated pediatric onco-hematology services for all stages of the clinical course (tumor board, intra and post-therapeutic monitoring), extension of genetic testing in pediatric cancers, radiotherapy for pediatric cancers, continuous and adequate access to pediatric oncology medication provided by current therapeutic protocols, connecting Romanian pediatric onco-hematology to major European healthcare and research platforms.

3. Mrs. President, you have extensive managerial experience gained from the coordination of the company and other professional associations of which you have been or are a member, but also from the coordination of the medical activity within the healthcare units in which you carried out your activity.

- What is your vision regarding the provision of specialized services to be provided to children with onco-hematological problems?

MDD: Pediatric hematology and oncology services should be provided throughout the treatment, as well as post-therapy, both for monitoring the disease, related to the risk of relapse or recurrence, but also for the late side effects of the disease and oncological treatments. Medical services must be customized according to the purpose of the treatment, curative or palliative. As there are significant differences between cancer therapy for malignant haematological diseases and solid tumors, it is desirable to have centers that treat only one of these categories of cancers, to provide patients with everything they need for diagnosis and treatment, according to current standards from the best hematology and pediatric oncology centers in Europe. The diversity of oncological conditions and locations requires multidisciplinary teams to collaborate on an ongoing basis. It is impossible for all specialties involved in oncological treatments to operate in a single medical institution, but

in cities with university clinics distance is not a problem. We don't want pediatric oncology centers to treat all cancers in one place. We must have dedicated teams of specialists from all surgical and non-surgical fields who intervene in the therapy of a patient, depending on the location of the cancer, with the availability of interdisciplinary collaboration. In very rare, difficult cases, for which there is no therapeutic standard yet, international collaboration is essential: either for a therapeutic decision or for taking over the patient if we do not have the opportunity in our country to provide the necessary therapeutic sequence. We currently have colleagues and friends in the best performing centers in Europe, ready to help us quickly and efficiently. It is one of the advantages of the centers affiliated to the European Network of Pediatric Oncology (ERN).

- What are the main areas of activity of this company?

MDD: In addition to organizing national and international scientific events, which aim to exchange experience with colleagues in the same specialty and specialties with which we collaborate, the National Register of Childhood Cancers is the most important permanent activity. Clinical research at the national level is still a goal that could not be achieved due to the small number of specialists, overwhelmed by the large volume of tasks they have, but specialists and pediatric oncology centers participate in international studies.

4. One of the activities initiated and developed by the company you lead is the establishment of the National Register of Childhood Cancers in Romania.

- What is the role of this register and how is it completed with other registers / records currently existing in the oncology field in Romania?

MDD: The primary mission of our registry is, like all cancer registries, to know the incidence of childhood cancers in our country and is also the foundation of cancer survival studies at the national level. Being a rare disease, with a long and complex clinical path (through several specialized centers), it is vital to aggregate cases nationwide and participate in the international case pool, so necessary for understanding the causes and developing the diagnostic and therapeutic arsenal in these diseases. In fact, the existence of a dedicated functional register is the first criterion of the European Quality Standards in Child Care with Cancer (SIOPE 2009) and, at the same time, an important condition to participate in international working groups and trials in pediatric oncology. Last but not least, validated knowledge of the number of cases expected each year by type of tumor is essential for substantiating health policies – and here we are referring primarily to national programs. Regarding the coverage and "how complete" the register is, it is a fact that, being fed exclusively by the specialized network of pediatric onco-hematology, it is necessary to periodically check this parameter – in English, "completeness" – fundamental for performance of any register. Since 2019, we have proposed to the Ministry of Health a "data flow" with the regional population registers of cancer (unsuccessful, so far). We are carrying out an

ecological "capture-recapture" study, through which we hope to identify cases that do not reach our specialized network.

- What stage are you in with the development of this register? What are the results so far?

MDD: Our registry was founded in September 2010 by the Romanian Society of Pediatric Onco-hematology and is developed in collaboration with the "Ion Chiricuța" Oncological Institute from Cluj-Napoca (with the technical support of specialists from the North West Regional Cancer Registry), being supported by exclusively non-governmental sources of funding. Since 2018, the register has benefited from an unprecedented mobilization of resources and energy brought by the collaboration with civil society (through the partnership with the "Give Wings" Association), which allowed the completion of national geographical coverage, retrospective completion of national case studies for the last ten years, the development of a modern digital reporting platform, at the forefront of Europe from this point of view, and our connection to the international data circuit. We are full members of the European Network of Cancer Registries (ENCR), an organization under the auspices of the EC, from which we requested an audit in 2021 (which is currently underway) to identify everything needed to improve and / or to correct in the development of the register. In 2019, we managed to calculate for the first time the national incidence rates (10.3 / 100,000 for the population 0-14 years in the period 2010-2019), and at the end of the year we managed to carry out the first survival study on national data (with the technical support of the Joint Research Center of the European Union), a study that places us exactly at the level of the average of the region (69.1% overall survival in Romania vs. 70% average in Eastern Europe). We are currently participating in several important international studies underway: the BENCHISTA study, which examines differences in survival between countries, and the PARTNER study, which investigates very rare cancers.

- What were the difficulties and opportunities encountered during the establishment of this register?

MDD: Being a non-governmental initiative, of course, both the continuity of funding and the ensuring a continuous and complete participation of pediatric onco-hematology centers are important challenges. The partnership with the "Give Wings" Association, a highly performing NGO (with involvement and recognition both nationally and internationally), was a big step forward in attracting funds, logistical support and all that communication means. Opportunities for the development of the registry were linked primarily to the long-standing concern of the European Union to encourage the development of cancer registries, but also to the understanding by civil society of the importance of our registry for the cause of children with cancer, bringing close to us The "Give Wings" Association, which, with an unconditional dedication, has long been committed to its support and development.

5. Dear Mrs. Dragomir, the child with oncological problems in the field of hematology is a

patient who has special needs and needs specific care, and the new epidemiological context generated by SARS-CoV-2 virus infection brings with it new managerial challenges at the level of organizational.

- How do you, as a specialist, perceive these particular needs?

MDD: The epidemiological procedures imposed by the risk of infection with the SARS-CoV-2 virus have changed the hospital circuits a little, but they are not much different from the ones we impose in the hospital and we recommend them at home to our patients. Restricting hospital visits, isolation from crowds and contact with sick people, home schooling, wearing a mask are measures to protect the cancer patient from any other infection that can be life threatening due to immunosuppression, due in part to the disease, in part to treatment.

Cancer patients infected with the SARS-CoV-2 virus have been and are being cared for in hospitals and wards dedi-

cated to this purpose at the national level, which have all the necessary therapies at their disposal. Oncological treatment with COVID-19 infection is not permitted, and its timing or discontinuation may adversely affect the course of the disease.

Fortunately, there have been few serious symptomatic cases among children with cancer in our country, probably as a result of family protection measures. Most of them were mild and moderate infections, with no complications at a distance that could aggravate the oncological disease. Unfortunately, we still know little about this infection, and the pandemic is not over yet. We learn from each other, from the experiences of colleges in the country and from pediatric oncology centers around the world. There are international digital platforms that update the issue of SARS-CoV-2 infection in children and adolescents with malignancies. So far, we have adopted all the prevention and treatment measures suggested by the International Society of Pediatric Oncology and SIOPE.

Text added on March 17, 2022

Because we are facing an unprecedented situation, the war in Ukraine, which has already generated catastrophic situations, I would like to make it known that the Romanian Society of Pediatric Onco-Hematology (SROHP) has joined international efforts (as SIOPE members) to cover the needs pediatric patients with malignancies, refugees or those seeking assistance. The Romanian Society of Pediatric Onco-Hematology, together with the "Give Wings" Association, organized a national collection and distribution service in specialized centers for children in Ukraine diagnosed with onco-hematological diseases. This service functions as a dispatcher that takes over centrally both the requests coming from the country and those coming through the European cooperation mechanisms (EWRS or UnicornHub) and distributes the cases in a coordinated way to the pediatric onco-hematology centers in the country according to the pathology, the necessary services and the available beds. Currently, the 6 pediatric onco-hematology centers in the country with the highest turnover of cases in Bucharest, Cluj-Napoca, Timișoara and Iași participate – with an estimated total of 60 beds. The dispatching service centralizes and continuously updates the available places at national level. Requests are taken over and processed by specialists and residents in pediatric onco-hematology using a digital application, developed by Code for Romania especially for this initiative. Through the same application, for the cases distributed in centers in our country that need help from a logistical point of view (transport, family accommodation, local support), the volunteers of the "Give Wings" Association identify and mobilize resources from the NGO and philanthropic sector.

This service can be accessed through:

- Telephone - unique number (40)724.024.229 (daily, between 08.00 and 20.00)
- Mail - ukrainechildcancer@srohp.ro; ukrainechildcancer@daruiestearipi.ro
- Contact form in Romanian, English and Ukrainian on the webpage www.ukrainechildcancerhelp.ro