

# INTERNATIONAL COOPERATION IN THE FIELD OF HEMATOPOIETIC STEM CELL DONATION



**Interview with:**

**Aurora DRAGOMIRIȘTEANU, MD, PhD and Director General of the National Registry of Hematopoietic Stem Cell Voluntary Donors (NRHSCVD)**

**EDUCATION AND TRAINING**

June 2011 - present, General Director of National Registry of Hematopoietic Stem Cells Voluntary Donors - NRHSCVD

- February 2011- August 2012, Project Team Leader, Project POSDRU /81/3.2/S/59348 "Quality and performance in the Romanian public health system"

- September 2008 -April 2010, Project Team Leader

Project financed by Swiss Development and Cooperation Agency (SDC) "Regionalisation of Intensive Care and Emergency Paediatric Services in Republic of Moldavia"

- July 2007 - September. 2008, Hospital Sales Manager Europharm Holding SA, Braşov

- August 2005 - June 2007 , Chief Medical Officer, Deputy General Director of Evaluation General Directorate

- July 2004 - August 2005, Project Manager, Project of Ministry of Health financed by UNFPA, USAID, UNICEF, OMS "Reproductive Health Survey - Romania, 2004"

UNFPA Office for Romania ([www.unfpa.ro](http://www.unfpa.ro))

- May 2003 - May 2004, National Coordinator

World Bank project "RO/4568 "Planning and Regulation of Health Service Delivery System", GVG, Germany

- April 1999 - April 2003, Chief of Consultancy and Training Department, Institute of Health Services Management

- January 1995 - April 1999, Resident Physician in the speciality of Public Health and Management, Institute of Health Services Management

**OTHER TRAINING:**

- 2012, PhD in Health Ethics, University of Medicine and Pharmacy "Gr. T Popa" Iasi, University of Medicine and Pharmacy "Gr. T Popa" Iași, „The ethics of resources allocation in Romania Health System"

- 2003, Senior consultant in Public Health and Health Management, University of Sibiu, Faculty of Medicine and Pharmacy, Sibiu, Romania

- 2002, Certificate of competence in "Health Economics and Financial Management", Institute of Health Services, Bucharest

- 1998, Specialist in Public Health and Health Management, University of Medicine and Pharmacy "Carol Davila", Bucharest, Romania

- 1996, MA in Health Services Management

LUMNY program - Institute of Hygiene, Public Health, Health Services and Management, Bucharest, London School of Hygiene and Tropical Medicine, Université de Montreal and New York University

- 1993, Medical Doctor, University of Craiova, Faculty of Medicine and Pharmacy, University of Craiova, Faculty of Medicine and Pharmacy, Craiova

**OTHER TRAINING** (certificat of participation)

- "41st Annual Meeting of the European Society for Blood and Marrow Transplantation",

- " ROMTRANSPLANT Congres 2014", "The XXII National Conference of Clinical Hematology and Transfusion" and "The 9 day of Balcanic Hematology",

- "1st international workshop on Challenges and Opportunities for the small and medium size bone marrow donor registries",

- "Update in Immunogenetics & Histocompatibility", workshop EFI,

- "Management of bone marrow donor" – EMC program organised by the University of Oradea and NRHSCVD,

- "Registry of Hematopoietic Stem Cells – present and perspectives" – workshop organised by the NRHSCVD and International Research Group on Hematopoietic Stem Cell Transplantation, France,

- "Quality Audit in Health Sector" – EMC program organised by SNSPMPDS București

- "The XXI National Conference of Clinical Hematology and Transfusion" and "The 9 day of Balcanic Hematology",

- „The XXI Congress of National Society of Radiotherapy and medical Oncology"

**Scientific activity:**

*Publications:*

-books and chapters in national and international books (ISBN)-author /coauthor – 12

-books and chapters in books (ISBN) - coordinator

-articles published in international journals ISI - Thomson Scientific – 3

-articles published in journals recognized CNCIS (B +) – 1

-articles published in journals recognized in Romania – 5

-other articles published in journals or presented in abstract specific volumes recognized in Romania and abroad - 14

-*Research Projects* - 4

-*Projects in Health management field* - 10

-*Projects in Education and training field* (director / responsible) - 11

**Affiliations:**

- since June 2014 - founding member of the Stem Cell Donor Registry.

- since April 2012 - member of the World Marrow Donor Association, active member of the following working groups: GRID (Global Identifier Registry for Donors), GEMS (Group of European Registries Medium Size), Prometheus Ethics.

- since October 2012 - member of the Romanian Society of Hematology.

- since February 1995 - member of the Romanian Association of Public Health and Health Management (1996 -2000 member of the Executive Committee/Office)

**Reporter:** *Madam Director, first of all, I would like us to briefly outline this field which you have been successfully coordinating for the past few years in Romania. Decision-makers, health professionals, as well as the general public are familiar with blood donation, but when it comes to the donation of hematopoietic stem cells (HSCs), a rather recent field, there are a few unclear issues I would like you to shed light on during this interview. I therefore propose we start with a few clarifying questions.*

- *What are hematopoietic stem cells and what are they used for?*

**Aurora Drogomirișteanu:** Stem cells are life's basic constituents. Stem cells have the capacity to turn into identical (self-renewal) or specialized stem cells, underlying the formation and renewal of any type of body cells. Hematopoietic stem cells (HSCs) are stem cells genetically determined to change into (functional) adult stem cells of the blood and the immune system. In Romania, the most popular method of harvesting HSCs is at birth, from the umbilical cord blood. A less known fact is that HSCs can also be harvested from the adults' peripheral blood, similar to the blood donation procedure, or from their bone marrow, through punctures of the wide pelvic bones while under anaesthesia.

HSCs are used to treat and cure patients with leukaemia or other types of blood cancer, autoimmune diseases or inherited metabolic disorders. More than 70 serious blood disorders can be cured through a transplant of HSCs obtained from a compatible donor, and in some cases this therapeutic procedure is the only life-saving chance that patients have.

**R:** *Who can donate hematopoietic stem cells?*

**AD:** Donors can be relatives of the patient, most likely a brother or sister, but also anyone not related to the patient's family who is willing to make a humanitarian gesture and save a life. Donors are adult individuals registered in the database of the National Registry of Hematopoietic Stem Cell Voluntary Donors (NRHSCVD), who can willingly donate stem cells until the age of 60, unless they are affected by severe health disorders. To register with the NRHSCVD as a potential donor, interested individuals have to be between 18 and 45 years of age.

The donation process is strictly confidential, both for the donor and for the recipient, a principle that we abide by rigorously. The donor and the patient become 'blood brothers', but they are not revealed each other's identity. Anonymous communication between patient and donor is possible only through the NRHSCVD which facilitates the exchange of messages, and ensures their translation if the patient is from another country.

**R:** *The National Registry of Hematopoietic Stem Cell Voluntary Donors is a public institution set up in 2011 under the Ministry of Health.*

- *Please describe to us the purpose and the main activities of the institution you are running.*
- *What were the challenges in establishing a Donor Registry in Romania?*

**AD:** The NRHSCVD's mission is to identify and ensure that compatible unrelated donors of hematopoietic stem cells are available for all patients in Romania who need a HSC transplant and lack a compatible related donor. The Registry has a centralized database of all individuals in Romania willing to donate HSCs, as well as all patients in need of a transplant who lack a compatible donor in their family.

One of the core NRHSCVD activities is processing the search requests for HSC compatible donors and supplying the HSC grafts used in performing transplants of HSCs from unrelated donors, in country and abroad. The search for an unrelated donor needed in a HSC transplant is a difficult process that involves various independent institutions; this is why perhaps our biggest challenge was to orchestrate the cooperation between all in-country partners: 21 HSC donor centres, 6 labs for HLA/ histocompatibility testing and screening for transfusion-transmissible infectious diseases, 3 apheresis centres, and 3 HSC transplant centres. In its capacity of technical assistance and management unit (TAMU) operating under the national health sub-programme 5.2 – "Transplantation of peripheral and central hematopoietic stem cells", in order to ensure financial sustainability, the NRHSCVD is no doubt challenged by the need to identify and select suitable donors through a process marked by efficiency and high standards of performance. At the moment, certain new services are still insufficiently regulated, such as the pre-donation medical evaluation of the HSC donor or the post-donation monitoring of the HSC donor. This and the issue of financing such services for the uninsured represent another challenge in implementing related international standards.

Another important NRHSCVD activity is organizing and maintaining a comprehensive database of HSC voluntary donors and of patients who need a transplant from an unrelated donor. This database is secure, in compliance with current relevant standards, and provides controlled and restricted access to the NRHSCVD authorized personnel and the units in charge of carrying out HSC donor recruitment, testing and donation. However, the NRHSCVD receives donor search requests for both national and international patients. Another challenge was to ensure the quality of highly complex processes which required standardizing and automating most of the procedures, while reaching consensus among all stakeholders. As it turns out, everyone stood to gain from this, particularly when the donor

or the patient was abroad, in which case we could resort to partners from any of the 53 countries with similar institutions. For ease of communication, the NRHSCVD staff responsible for those activities that entail international cooperation speak English fluently and often a second foreign language as well.

Staying connected to similar international bodies is an ongoing challenge for the NRHSCVD, because international standards are constantly updated, and therefore, their adequate enforcement calls for the NRHSCVD staff to keep abreast of the latest associated clinical benefits and economic impact.

**R:** You mentioned that one of the challenges was to ensure cooperation in the field of HSC transplantation, which called for considerable efforts on your part.

- Why is cooperation key to hematopoietic stem cell transplantation? And,
- How is it made possible?

**AD:** Cooperation in the field of transplantation is key because it provides an open channel of communication with the related international community, as well as access to international databases of potential HSC donors and recognition of the Registry as an institution that upholds international working standards.

The NRHSCVD is a member of the World Marrow Donor Association, an organization responsible for setting up consistent and quality standards to be followed by registries worldwide.

At the same time, the NRHSCVD is interconnected with the European Marrow Donor Information System (EMDIS) international member registries and is a member of Europdonor - Bone Marrow Donors Worldwide (BMDW), an international organization present in 53 countries working together to generate a centralized global database of all potential HSC volunteer donors. This cooperation is vital for patients in need of a peripheral stem cell transplant, given that, in almost 50 per cent of these transplants, the donor and the patient come from different countries.

We are also members of the European Society for Blood and Marrow Transplantation (EBMT), a non-profit organization established in order to allow scientists and physicians involved in clinical hematopoietic stem cell transplantation to share their experience and develop cooperative research studies. The EBMT aims to promote all aspects associated with the transplantation of haematopoietic stem cells from all donor sources and donor types including basic and clinical research, education, standardisation, quality control, and accreditation for transplant procedures.

Cooperation in the field of HSC transplantation becomes possible because the NRHSCVD has adhered to the values and standards advanced by these organizations and has applied them nationwide at the level of organizations and relevant legislation.

**R:** The September agenda also includes the “World Marrow Donor Day”. At international level, this day is celebrated through special events designed to promote and raise awareness among the general public with regard to the potential benefits of HSC transplantation. Please tell us how you plan to mark this day here, in Romania.

**AD:** Because the number of donors registered in BMDW recently surpassed a record 25 million, a World Marrow Donor Day will be celebrated worldwide this year, on 19 September. The celebration will start in New Zealand and end in Hawaii.

Romania will also celebrate this day as the NRHSCVD joins the international initiative. Starting 19 September, for one week, the capital city and other ten large cities in the country will host a caravan of events for the general public, including the dissemination of information materials on HSC donation, contests, and meetings with patients, donors and volunteers. We will also be present on social media to interact with those interested in the event and the NRHSCVD activity.

This year’s World Marrow Donor Day theme will be “25 million donors”. As such, this day will be an opportunity to thank all the 25 million volunteer donors worldwide whose gesture saved a life.

**R:** Madam Director, we know you as a dynamic person who distinguished herself through professional achievements and the ability to develop highly-efficient systems in her previous work places. You served several noble causes and your efforts were always defined by dedication and passion.

- Looking ahead, what are the targets that you, as general director of NRHSCVD, would like to reach?

We wish to do our part in raising awareness among the general public with regard to HSC donation and the NRHSCVD activity, leading, with time, to an increased number of potential donors registered in our database and, of course, to increased life-saving chances for patients in need of a HSC transplant.

*Interview conducted by Marius Ciutan*