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PATIENT POINT OF VIEW

*Open access*

# Advocating for Hope, Access, and Future in Rare and Paediatric Cancer Patients

Ana Pataki

### 1.1. Personal Motivation

At the very beginning of my journey as a patient rights advocate, I was "just" a mom. My son was diagnosed with Langerhans Cell Histiocytosis in 2017, and he completed his treatment in mid-2019.
Throughout that journey, we had valuable communication with his doctors, who answered all of our questions regarding symptoms, support, the course of treatment between chemotherapy cycles, and how to strengthen his immune system during therapy.
This experience was quite intense and frightening for us at the time, but we could not envision any other scenario than the one that led to a positive treatment outcome. Our fight ended in victory.
At the very end of treatment at the Institute for Child and Youth Health Care Vojvodina, Paediatric Clinic in Novi Sad, we returned to our "new normal"—but nothing was the same, nor did it feel normal anymore.

An important part of our journey was communication and support:

- First and foremost, **communication with doctors**, who guided us through every step - from the initial diagnosis, through explanations of the treatment protocol, side effects, and the risks that might arise. Every step was communicated in advance, with continuous check-ins to address questions and doubts during treatment. Our path to recovery lasted about two years, with regular hospital visits, home blood monitoring, maintenance therapy that lasted for a while, and annual check-ups coordinated with the attending physicians.
- **The psychological support** we received during treatment. This occurred once a week through a program called "A Cup of Conversation," organized by the National Association of Parents of Children with Cancer "**NURDOR**". Psychologists on the ward hosted weekly group sessions for parents and guardians, giving everyone space to ask questions, share doubts and concerns, or simply express worry and sadness. It is deeply meaningful to feel that someone is there to listen - that you are seen and heard. As simple as it may sound, a parent's identity often gets lost in the daily struggle for their child's recovery and we become a support system by the bedside for our child or family member, and less of a spouse, sibling, or daughter - putting all other relationships on hold until we get the answers: a diagnosis, a therapy, or recovery. What I realized while staying in the hospital with my child is that not all of us have the same capacity to face fear and questions that arise - especially when a family member needs help and there is little we can do to speed up the healing process. What we can do is create conditions for treatment to proceed smoothly, convey love and support, and walk the path together.
- **Community support**: Only about 5% of rare diseases have an available therapy, and our child was among that 5%. According to Global Genes[1], around 30% of children diagnosed with rare diseases or paediatric cancer do not live

[1] Source: Global Genes, https://globalgenes.org/rare-disease-facts/?gad_source=1&gad_campaignid=2080237801&gbraid=0AAAACthKWbQJp7qiFKZg38Uds-Gl8bWKp&gclid=Cj0KCQjwvajDBhCNARIsAEE29WqmaqbutmkipmNXpAvXzkaD2jkWteoZZi7qK9vDaBM3aRMx7cl9u4gaAsRYEALw_wcB, date of access July 13th 2025.

to see their fifth birthday, which is why all these diagnoses are categorized as rare. What we didn't know at the beginning of our son's treatment was that for 95% of rare diseases, there is no available therapy. Not only in Serbia but globally, for the rest of 95% of rare diseases. That is why communication with the rare disease community is so valuable. Our attempts to meet other patients with the same diagnosis led us to events, meetings, and spaces where we met courageous parents and rare diseases patient advocates who had overcome their challenges and turned them into solution proposals.

- Our motivation is to offer a space for others - a place where people can ask questions, propose solutions, and highlight the everyday challenges they face. In September 2022, we launched the **podcast** Rare and Share[2], which created a platform for sharing personal experiences of patients when dealing with diagnoses, as well as parents who "moved mountains" for their children - whether by advocating for legal changes, introducing therapies, or introducing new diagnoses in newborn screening programs, as it was the case with the inclusion of Spinal Muscular Atrophy in September 2022.

### 2.1. Informal Education Toward Patient Advocacy

Learning is a continuous process, but it is the only way to gain the arguments that allow you to seek new solutions to the challenges faced by patients with rare diseases and paediatric cancers. That is why, after completing my formal education, I have focused on informal learning when it comes to patient advocacy.

In order to better understand the complexities of clinical trials and scientific innovation, I attended the Winter School of Scientific Innovation and Translational Research in 2023, organized by EURORDIS – **the European Organisation for Rare Diseases**.

Continuing this educational journey on the topic of regulatory procedures and the terminology by which drugs and medical devices obtain agencies permits, I completed a training program for patient representatives organized by the **European Capacity Building for Patients** (EUCAPA).

This education gave me the skills, tools, insights, and expertise I needed to take part in joint clinical assessments and scientific consultations, especially in the context of the EU HTA (**Health Technology Assessment**) regulation.

After that, I began training to become a Patient Expert through the **European Patients' Academy on Therapeutic Innovation** (EUPATI). I earned my certification after one year and 28 lessons covering six different modules. Additional benefit of this journey was the network of collaborators I met, coming from various parts of the world - people who can help connect and empower patient advocates working to improve the quality of life for patients with paediatric cancers and rare diseases.

The goal of creating **European Reference Networks** (ERNs) is to ensure that **information** travels instead of the patient, thereby reducing the costs associated with transport and hospital treatments. On the other hand, the exchange of experiences and expertise among specialists can significantly improve the quality of care provided at expert centers.

This is where I see the role of **patient advocates**: to connect individual patients, doctors, and rare disease treatment centers by sharing critical information when, maybe, those centers may lack the capacity to share these information in language that is comprehensible to patients.

After one year and obtaining a certificate from this prestigious European organization, I was invited to join the Patient Expert Training Committee that prepares the curriculum for the next generation of patient advocacy experts, contributing with insights from my own experience and sharing the information I gained working with organizations supporting patients with cancer and rare diseases.

### 3.1. Professional Choices

I aligned my professional choices with the value system I built through personal experience and further specialization in the field of patient advocacy.

Aware that many parents today are faced with a diagnosis of paediatric cancer or a rare disease for their child, often with their minds overwhelmed by questions, I set my priorities around finding answers I could offer as clear guidance, with the aim of helping others navigate this journey by providing concrete, relevant information that could lead more quickly to a diagnosis or potentially available treatment for specific diagnosis.

Through communication with healthcare professionals from various specialties, it became clear that the more experience and case studies they have, the faster they can respond in terms of establishing a diagnosis, directing patients toward the right answers, and reacting efficiently when administering treatment.

[2] Podcast Rare and Share: www.rareandshare.net

That is why I believe in the "power of communication", as science and technology progress, access to information has become easier and faster. However, with the development of clinical trials, the flow of information can sometimes become overwhelming. For this reason, clear and precise guidelines in the context of diagnosing and treating rare diseases are essential.

By sharing experiences between doctors, patients can often receive a diagnosis in a shorter timeframe, based on clinical practice. At the same time, researchers involved in clinical studies can use this information to find more accurate solutions for various gene mutation variants treatments that cause rare diseases or enzyme deficiencies, addressed through gene therapies or medications developed in such clinical studies.

In collaboration with associations representing patients with rare diseases, I am currently working on activities such as:

- awareness-raising campaigns,
- development and implementation of communication strategies,
- organizing events that connect patients, and
- organizing continuing medical education for healthcare professionals from various specialties related to rare diseases.

My motivation to learn more about rare diseases, as well as about ways to accelerate diagnosis and shorten the time to treatment, grew out of the desire to never again feel the helplessness that overwhelmed me when I first heard my child's diagnosis.

I learned out of a need to "arm myself" with knowledge, to master the terminology used, even without prior medical educationand to apply the skills I do possess when presenting the daily challenges faced by patients diagnosed with rare diseases.

These educational experiences have taken me to different places that were previously out of my reach, whether in terms of geography or in terms of connections I have established with representatives from other rare disease organizations. The result of this exchange of knowledge are regional alliances and collaboration on joint projects over the years.

I have made all the knowledge and skills I have acquired available to anyone with the questions, so that together we can work toward a diagnosis, treatment, or solution to the situation they find themselves in. My reward is to help every family that reaches out for help, directing them to the right address or connect them with doctors of a certain specialty who can provide adequate health care.

### 3.2. How the Podcast "Rare and Share" Was Created

After appearing on the national television program "Mesto za nas" (A Place for Us), and following the strong public reaction and the large number of messages we received from parents, we realized that there was a lack of public platforms where experiences could be shared in a way that empowers parents to ask questions. There was a lack of means to convey the experience in a simple, comprehensible language.

For the past three years, I have been creating content for the podcast "Rare and Share," which we created to share personal stories of patients with rare diseases and of parents who, in their search for therapies or by lobbying for the amendment and passing of the law, quite literally "moved mountains" for their children.

We've had the opportunity to speak with professionals who shared, from their perspectives experiences and advice on how to improve the quality of life for patients.

In the field of oncology, some of our guests were:

- Irina Ban, "Zvončica": A devoted mother with over 30 years of experience in creating a safe environment for children undergoing cancer treatment and their parents. In cooperation with doctors and with knowledge gained in the field of paediatric cancer patient rights, "**Zvončica**" – the Association of Parents of Children with Malignant and Other Rare Diseases was founded in 1992. That same year, the first parental house near the Institute for Mother and Child Healthcare "Dr Vukan Čupić," was opened and still operates today near the Institute. Irina shared her journey from personal fight for her child's recovery to transferring knowledge from international organizations to local doctors, through her work with patients and families staying in the parental house.
- Joland Korora – A woman recognizable as the face of **NURDOR** (**National Association of Parents of Children with Cancer "NURDOR"**). Her son Luka was treated for embryonal-type nephroblastoma at the age of three, and twenty years later, leads an "army" of volunteers dedicated to improving the quality of life for patients through various projects, five parental houses, and fundraising efforts for dignified treatment. NURDOR participated in the **Law on Health Insurance** amendments, and changes in the right to free rehabilitation of children who have undergone chemotherapy. Before NURDOR's initiative, parents of severely ill children had the right to only **four**

**months of paid leave** with **65% salary compensation**. After five years of fighting, the 2017 Draft of the Law and the official amendments in 2019, two major changes were introduced: unlimited sick leave for parents **until the child turns 18** if the child has a serious condition (like cancer or brain injury and alike) and **100% salary compensation** instead of the previous 65%. These changes were formally adopted in the Law on Health Insurance (*Official Gazette of RS, No. 25/2019*), which came into effect on April 11, 2019, and were publicly recognized as a direct result of NURDOR's pressure and advocacy efforts. NURDOR became the driving force behind the changes in law that allow parents to remain by their seriously ill child's side until adulthood, with full salary compensation, from parents' motives to help families facing financial and procedural challenges, based on their own experience.

- **Vukašin Čobeljić**, Psychologist at the University Children's Hospital Belgrade "Tiršova". One of our guests who shared professional insights into working with families facing cancer diagnoses, was Vukašin Čobeljić – with the intent to introduce the viewers to the psychologist's role in delivering terminal diagnoses and the psychological tools used to help families cope with loss of the family member. Vukašin also spoke about his volunteer work with NURDOR and described the professional journey of colleagues who choose to work at the Hemato-Oncology Clinic at UCH Belgrade"Tiršova".
- **Prof Ana Banko, PhD** – ROLLERS Project - A specialist in microbiology and parasitology, a subspecialist in virology, and associate professor at the Institute of Microbiology and Parasitology, Faculty of Medicine, University of Belgrade. In addition to her work on the ROLLERS project - which examined the link between the Epstein-Barr virus and rheumatoid arthritis, supported by the Science Fund, she joined our podcast "Rare and Share" to discuss the role of the HPV vaccine and the importance of prevention in cervical cancer. Our conversation addressed the power of individuals to ask questions, developing critical thinking, and engaging in open communication with doctors about personal health. The power of knowledge lies in understanding that detecting cancer at an early stage allowes more treatment options, a higher chance of cure, and treatments that medical oncologists can approach almost as chornic diseases.

### 4.1. Where to From Here?

When faced with devastating news such as a **cancer diagnosis**, we all respond in similar ways, we feel fear, sadness, helplessness, and sometimes even anger. However, the way we confront with a new situation can be a crucial factor in the recovery process.

Patient organizations made up of women who have survived different types of cancer possess valuable experiences and are ready to share, are trained to offer information, assistance, and support to those who have just learned about the diagnosis or are currently undergoing treatment.

One such organization was founded by **Vesna Bondžić from Vrnjačka Banja**, who named it after her grandmother: "**Women's Center Milica**", after her own personal experience. This center provides invaluable support for every woman who finds herself in what may seem like a hopeless situation following a diagnosis of gynecological carcinoma.

In October 2023, the first **National Center for Support and Education for Women Diagnosed with Breast and Cervical Cancer** was opened in Belgrade, empowering its members with access to information and support.

In addition, "Women's Center Milica" created a **guide to breast cancer treatment called "My Assistant",** as a kind of reminder of all the steps that women go throughout the healing journey. As part of the National Center for Support and Education for Women Diagnosed with Breast and Cervical Cancer, a telephone support line is available during treatment: 0800 40 40 40, Monday through Friday, from 10 AM to 2 PM. Calls are answered by trained coordinators from Women's Center Milica, women who have completed their own treatment and received accredited training by members of the Association of Medical Oncologists of Serbia. In this way, the helpline can provide all the information to callers that is important for the preparation of therapy, explanation of procedures, but also for emotional and experiential support to women who call this phone number.

"Women's Center Milica" is also actively involved in public advocacy campaigns and communication with decision-makers, working to improve the quality of life for women by pushing for the inclusion of innovative therapies in treatment protocols for breast and gynecological cancers. At the end of 2023, following the initiative of "Women's Center Milica", the **Republic Health Insurance Fund** (RFZO) officially accepted patients' organization proposal with the aim of accepting initiatives to add an innovative therapy to the reimbursement list for the treatment of three subtypes of breast cancer patients.

This patient organization has long been a member of professional networks such as **ESMO** (**European Society for Medical Oncology**) and **ENGAGe (European Network of Gynecological Cancer Advocacy Groups)**, actively participating

in conferences where they share patients experiences with medical oncologists, surgeons, radiologists, and physicians from various specialties. The goal is to provide more insight into the effects of therapies and the best approaches for supporting women on their path to recovery, because every experience is, in fact, an opportunity for learning. The members of this organization turn that shared experience into strength, so they can offer genuine support to every woman facing this journey.

A quote often attributed to **Jovan Jovanović Zmaj** says: "Knowledge is the only thing that grows by sharing."

That is why I thank the Serbian Association for Cancer Research for the opportunity to share my experience, from being "just" a mom to becoming an expert in the field of patient advocacy, and to offer my support to anyone who believes I may have answers to the questions they are interested in.

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*Ana Pataki, MSc*