

A blood cancer patient's long road to diagnosis

Ilona, a patient living with polycythemia vera, shares her experiences with this rare blood cancer

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Myeloproliferative neoplasms (MPNs) are a group of rare blood cancers, including myelofibrosis (MF), polycythemia vera (PV) and essential thrombocythemia (ET), that affect blood cell production in the bone marrow. These blood cancers may result in debilitating symptoms that can burden daily life. Unfortunately, patients often struggle to have their needs met when confronting their illness. The good news is, people all over the world living with MPNs, their caregivers and clinicians are working together to understand the unique physical, emotional and economic challenges that the MPN community faces. Ilona, a woman from Germany living with PV, shares her story below.

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Ilona, an active event manager, has always been diligent about maintaining her health so that she can keep up with her busy schedule. Routine care before a planned surgery revealed abnormal blood tests. Like so many people with MPNs, doctors struggled to identify the source of her problem. Ilona's symptoms included fatigue, pain and inflammation. Eventually her worsening symptoms restricted her everyday life. She would work in the mornings but would be too tired to continue in the afternoon.

Hope for Ilona began when she was correctly diagnosed with PV. She read about her disease and educated herself, and also shared her learnings with her family and those around her. Once they understood the challenges she was facing, the emotional burden and isolation of living with an MPN began to lift. Through working with her health care providers, Ilona found a treatment that has improved her quality of life. She is now able to manage her illness and spend meaningful time working and with family.

Although MPNs can be difficult to identify and diagnose, the hallmark of the disease, fatigue, is not. Even after diagnosis, living with these symptoms can cause emotional distress. In a global survey of patients with MPNs, up to 61% of respondents indicated that they felt some level of depression during the last month due to their condition. This is often caused by interruptions to their daily life, including social life, patients' relationships with their caregivers, and the fact that pain and discomfort cause people with MPNs to limit their daily activities. Furthermore, 36% of people with an MPN are impaired at work, adding an economic burden that can worsen the stress a person is already facing while living with their disease.

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A key tool for easing the emotional, economic and interpersonal distress that people with MPNs face is raising awareness about this group of cancers. One of the most frustrating but avoidable challenges for those who suffer from MPNs is underreporting of their symptoms. "My family didn't understand until they worked hard to learn more about it," said Ilona.

Fostering an environment where physical and emotional discomfort are discussed means patients are much more likely to get the care they need. With this heightened awareness of patient perspectives, there is an opportunity to improve communication and understanding across the MPN community to collectively help shape and optimize patient care.

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