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# Rare Every Day: Experiences, challenges and victories of the rare disease community

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While each person living with a rare disease has a unique story, the collective experiences of the community often resonate with the broader group. In support of Rare Disease Day (February 28) this year, Novartis is adopting the theme “Rare Every Day” to provide a unifying voice and to enhance awareness and understanding of the experiences, challenges and victories that members of the rare disease community face daily. Following is a look at a few “Rare Every Day” experiences from members of the rare disease community.

Similar to others living with certain rare diseases, many with a neuroendocrine tumor (NET) experience symptoms that impact their everyday life. NETs are a rare type of cancer that arise in different tissues and organs throughout the body that contain neuroendocrine cells. There are many types of NETs that can occur throughout the body; however, most are found in the gastrointestinal tract, pancreas and lungs. Grace Goldstein, the COO of the Carcinoid Cancer Foundation (CCF), has spoken with thousands of patients with NETs, many of whom noted that everything from changing energy levels and making dietary changes can significantly impact their daily life. The First Global NET Patient Survey [1], a collaboration between the International Neuroendocrine Cancer Alliance (INCA) and Novartis, shined a light on the common experiences of NET patients (1,928) around the world. Nearly all (92%) survey respondents stated that they made lifestyle changes because of their NETs (including diet, work, physical activities, and social life). This experience can be common for people living with a rare disease, which may impact their lives in ways they didn’t initially account for, but it’s important to know you’re not alone in this lifestyle adjustment.

With rare diseases, it also can be common for patients to feel uncertain upon diagnosis, as they often know little or nothing about their disease prior to diagnosis. In 2007, Tina F, was diagnosed with myelofibrosis (MF), one of a group of incurable, rare blood cancers called myeloproliferative neoplasms or “MPNs.” She recalls her feelings upon diagnosis, “During the first few months after my diagnosis I felt scared and alone – I had never heard of MPNs, and my initial research made me feel worried and confused.”

MPNs are malignant conditions which disrupt the normal production of blood cells by the bone marrow and can result in burdensome symptoms such as fatigue, night sweats, bone/joint pain and more. The MPN LANDMARK Survey [2], featuring nearly 700 patients across six countries and four continents – the first-ever international survey conducted by Novartis – supports Tina’s sentiment, finding that approximately one-third of patients in the study reported feeling anxious or worried about their disease, and unsure of what radical life changes the future may hold.

Novartis has remained committed to the rare disease community by providing resources to help increase awareness and education and continuing to conduct research in rare diseases. To learn more about the everyday experiences of living with rare diseases, search the hashtag #RareEveryDay on Twitter.


1. Singh, Simron et al. Patient-Reported Burden Of A Neuroendocrine Tumor (NET) Diagnosis: Results From The First Global Survey Of Patients With Nets. Journal of Global Oncology 3.1 (2017): 43-53. Web.
2. Harrison C, Koschmieder S, Foltz L, et al. The Impact of Myeloproliferative Neoplasms (MPNs) on Patients’ Quality of Life and Productivity: Results from the International MPN LANDMARK Survey.

Abstract #4267. 58th ASH Annual Meeting & Exposition of the American Society of Hematology (ASH) San Diego, California, 2016.

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