

MPN Horizons: The Voice of Younger MPN Patients

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Introduction: my MPN journey



Age 9 - Migraine with aura



Age 18 - Last day at school



Age 18 - Off to university



Introduction: my MPN journey



Age 21 - Diagnosed with ET



Age 22 - Graduation!



Age 26 - Submitting my PhD



Introduction: my MPN journey



Age 26 - At Guy's Hospital



4 patient initiatives that have helped me so far

1. MPN Voice Patient Forums

- Meet and connect with fellow MPN patients
- Share personal stories, symptoms, and lifestyle tips
- Hear and learn from leading clinicians
- Find out more about MPNs, the latest research, and drug trials



2. MPN Voice Buddy System

- Connect with another young MPN patient
- Share symptoms and lifestyle tips over the course of your MPN journey
- A sounding board for any questions, anxieties, and uncertainties
- Exchange thoughts and experiences about managing an MPN with school, university, or apprenticeships, as well as applying for jobs and navigating the workplace



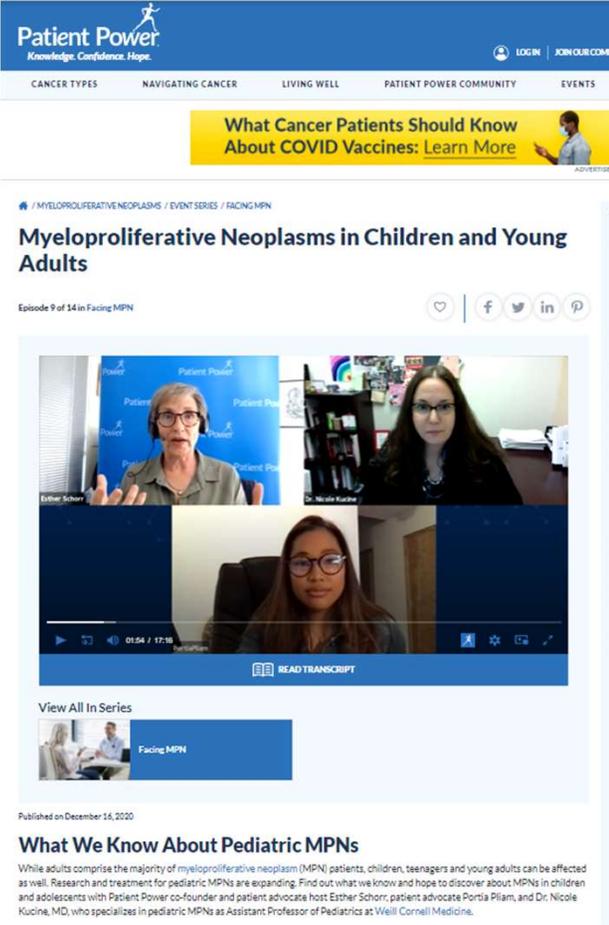
3. Teenage and Young Adult Clinic at Guy's Hospital

- Integrated healthcare designed for young cancer patients. A holistic approach that treats you as a whole person:
 - Haematology Nurse
 - Psychologist
 - Dietician
 - Gynaecologist
- Regular texts and phone calls with a nurse who helps manage appointments and liaises with your haematology team



4. MPN videos and information resources

- Learn more about MPNs from consultants and patients around the world
- Take advantage of their expertise across a range of subject areas
- Participatory sessions enable you to ask questions and receive answers
- Being your own advocate: “Knowledge is the best medicine of all”



The screenshot shows the Patient Power website interface. At the top, the logo reads "Patient Power Knowledge. Confidence. Hope." with navigation links for "CANCER TYPES", "NAVIGATING CANCER", "LIVING WELL", "PATIENT POWER COMMUNITY", and "EVENTS". A yellow banner below the header says "What Cancer Patients Should Know About COVID Vaccines: Learn More". The main content area is titled "Myeloproliferative Neoplasms in Children and Young Adults" and is identified as "Episode 9 of 14 in Facing MPN". It features a video player with three participants: Esther Schorr, Dr. Nicole Kucine, and another woman. Below the video is a "View All In Series" section and a "Published on December 16, 2020" date. The article title is "What We Know About Pediatric MPNs" and the text discusses the expanding research and treatment for pediatric MPNs, mentioning Patient Power co-founder Esther Schorr, patient advocate Poria Pilam, and Dr. Nicole Kucine.



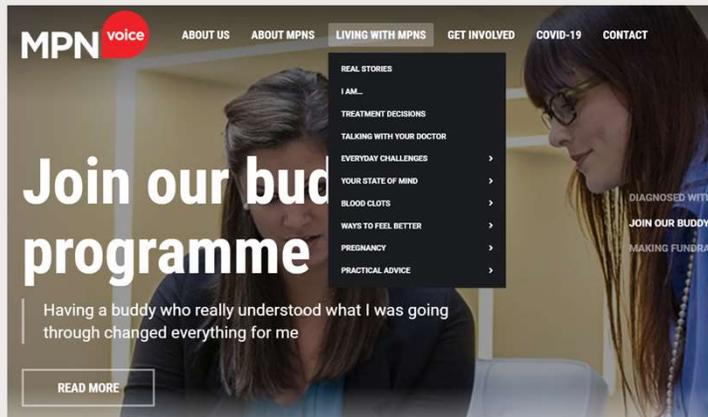
4 ideas for young patient advocacy in the future

1. Offer a patient forum
designed and delivered
specifically for young MPN
patients and their families



- Young MPN patients can feel like a minority within a minority community
- Young patients and their families are likely to have additional and specific questions about:
 - long-term treatment plans
 - living with a chronic illness
 - disease progression
 - why majority develop MPNs at 50/60 years of age
- All of which have a very different optic at the beginning of someone's life, relative to receiving an MPN diagnosis later in life

2. Devote a section of your MPN website to young patients



- Visibility is key. Ensure young patients feel seen, heard, and understood when reading information about their diagnosis
- A space where clinicians could address FAQs from young patients in their clinics
- A space where young MPN patients could share their stories and experiences
- Begin to redress an imbalance whereby information and guidance is weighted towards patients diagnosed later in life

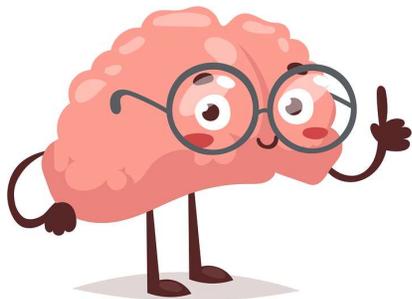
3. Fund and/or recruit a specialist nurse to support and monitor young MPN patients



- A point of contact and continuity for young patients who are likely to need a different kind of support
- A nurse who can communicate with young patients via text, WhatsApp, or phone call
- Someone who has experience working in paediatrics or teenage and young adult care
- Someone who is embedded in a young patient's healthcare team and can help them navigate between different departments

4. Team up with psychologists to offer young MPN patients support and resources for managing and living with a chronic disease

- Psychologists can support young MPN patients who receive a cancer diagnosis at a young age
- Someone who can teach young patients therapy techniques, such as ACT or mindfulness, that can help them manage a chronic disease and reduce inflammation
- Professional support for young patients' uncertainties around living with an MPN, managing symptoms, undergoing scans and tests, future disease progression, and weighing up treatment options





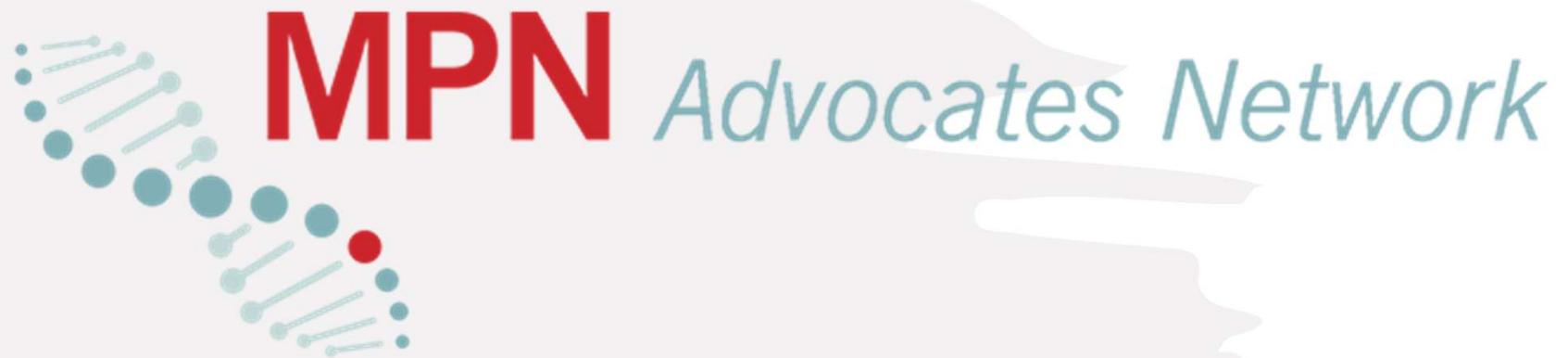
Advocacy for young MPN patients in a Covid-19 world



Advocacy for young MPN patients in a Covid-19 world

Facilitate virtual events, create discussion spaces, and offer resources that address living with an MPN as a young person in a Covid-19 world:

- How might charities work together with consultants to gather patient information to assess young patients' risk relative to older patients' risk?
- What does clinical advice to “be cautious” look like for an MPN patient attending school or university, or entering the workplace at the beginning of their career?
- How can young patients be supported in this effort when their friends and close contacts have returned to “normal”?
- What resources might help young patients navigate social media and “fear of missing out” when balanced against their risk to Covid-19 as someone diagnosed with blood cancer?



Thank you for listening

Alice Watson