



MPN VOICE YOUNG PATIENTS' FORUM – LONDON

Saturday 21st June 2025

1.30 – 2.00	Arrival/registration – with pizza & refreshments
2.00 – 2.15	Overview of MPN Voice and its Young Patient Community Nona Baker, Co-chair, MPN Voice and Alice Watson, MPN Voice Young Patient Network
2.15 – 2.30	Introduction to MPNs in Young People (research and stats on prevalence, disease type, symptoms, treatment progression, what is in the pipeline, looking to the future)
2.30 – 2.45	Overview of MPNs and A-Z of terminology (ET/PV/MF, gene mutations and what they mean, symptoms profiles for each, treatment options)
2.45 – 3.00	Menstruation, Fertility and Pregnancy for Young People with MPNs (periods, fertility considerations, contraceptives, pregnancy, risks, familial inheritance)
3.00 – 3.15	Psychological Impacts of a Chronic Illness and Introduction to Acceptance Commitment Therapy (impact of diagnosis, future uncertainty, managing a chronic condition, value of ACT, practical participatory ACT exercise)
3.15 – 3.30	comfort and refreshment break
3.30 – 3.45	Lifestyle Tips for Living with a MPN (schooling, career planning, workplace entitlement, disability allowances, diet, physical activity, travel considerations)
3.45 – 4.00	Research Study into Young Patient Experiences of Being Diagnosed and Living with a MPN (Research context, aims, methodology, findings, outcomes, future directions)
4.00 – 4.15	Patient Speaker – TBC
4.15 – 4.30	Patient Speaker – TBC
4.30 – 5.15	Q&A – all participating clinicians
5.15 – 6.00	Break-out groups where ET, MF and PV patients can meet in smaller groups to discuss everyday challenges and swap tips. Plus a group where partners/family/friends can meet to discuss everyday challenges faced by the patient and themselves