

MPN Voice

A brief history

MPN Voice – the beginning

- Started informally in about 2002 by a group of 5-6 patients who were under the care of the same Haematologist at Guys and St Thomas' in London – Professor Claire Harrison
- Aims were initially to provide:
 - Reliable and up-to-date information
 - Patient-to-patient contact
- At first, we simply met approximately every 6 months in a meeting room at the hospital

MPN Voice – early growth

- First website was about 6 pages, mostly about the conditions and their treatment
- Production of printed material with medical information
- The meetings became larger (20-30 patients and carers)
- Fundraising activities started (individuals and small groups) – the money mostly went to pay for printing

MPN Voice – formal establishment

- We became a recognised group under the umbrella of a UK registered charity based at Guys and St Thomas' hospital - enabled us to receive larger amounts of funding from a few corporate and family trust donors.
- 2nd generation website with more pages, professionally produced
- Establishment of the buddy network for peer-peer support
- A few meetings outside London, based around regional centres of MPN expertise
- Larger fundraising events

MPN Voice – ongoing

- Research support – funding of an initial phase of an epidemiology study
- Regular regional meetings
- 3rd generation website
- Bi-annual full day conference for 200+
- Advocacy activity – representation at NICE HTAs
- Focus remains on patient support, information and patient contact
- Approximate annual turnover £200k

MPN Voice – lessons learned

Enabling factors

- Committed individuals
- Simple, achievable aims
- Operation under an umbrella legal entity
- Gradual growth

Challenges

- Most activity is voluntary (only 1 part-time paid person)
- Informal responsibilities
- Donor information can be hard to obtain
- Highly dependent on a few individuals