

MPN HORIZONS

BELGRADE 2016



MPN Alliance Australia
Empower • Enrich • Enliven

MPN HORIZONS 2016

□ MPN Alliance Australia

- Lara Chapman - Founder
- Diagnosed with ET in 2008
- Lack of MPN related information
- Contacted Leukaemia Foundation in 2013
- Established local support group
- Raised \$40,000 in fundraising – Donated \$24,000 to MPN Research in Queensland



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New or Existing Organisation?

- Difficult finding volunteers to participate
- Logistical challenges
- Differing visions and goals
- Legal & Administrative burden of setting up a new organisation
- Inexperience with fundraising & legislative obligations

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- **Partnership with Existing Organisation**
- Informal arrangement
- Utilise existing experience and networks
- Utilise IT infrastructure
- Maximise the efforts of MPN patient volunteers
- Minimise time & money spent on ongoing administration and compliance
- Mutual benefit for both organisations

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☐ Terms of Reference and Code of Conduct

- Establish who we are
- Brainstorm & determine our Mission, Vision, Goals and Guiding Principles
- Set expectations and agree on the team's Code of Conduct, both within and outside of the team
- Intellectual Property
- Provides greater assurance to our partners
- Memorandum of Understanding with LFA

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□ Achievements

- Submissions to the 2015 Senate Committee
- Set up of MPN AA Website & FaceBook page
- Fundraising of approx A\$20k this year
- Supportive Partnership with MPN Australia and New Zealand patient Facebook page
- Involvement in International meetings & partnerships with International MPN organisations

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□ Challenges

- Workload & email traffic is onerous at times
- Restrictions due to illness burden
- Major organisational change with our partnership organisation
- Establish fundraising strategy for long term support & sustainability
- “Keeping on the same page” within our team