

Welcome

Jon Mathias – MPN Advocates Network

Welcome and Thank You

- This meeting is the biggest milestone so far in an ongoing journey that started about 4 years ago with a conference call of a few MPN Patient representatives
- The idea was to form a network for MPN Representatives to collaborate and share
- Progress has been sporadic, but I believe we now have something sustainable and energised

Thank you to:

Our sponsors:

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Our Steering Committee who have planned the event:

- Felice Bombaci
- Bill Crowley
- Ilse Jans
- Peter Loffelhardt
- Giora Sharf
- Cheryl Petruk
- Robi Zelig
- Werner Zinkland

Thanks also to:

- **Our Expert Clinician Speakers**
- **The Leukaemia Patient Advocates Foundation**
 - Giora Sharf and Jan Geissler
- **Liberty logistics agency**

And lastly...



Without Frans, none of us would be here today

Frans Pross
1952-2013

Patient Advocacy



Clinicians



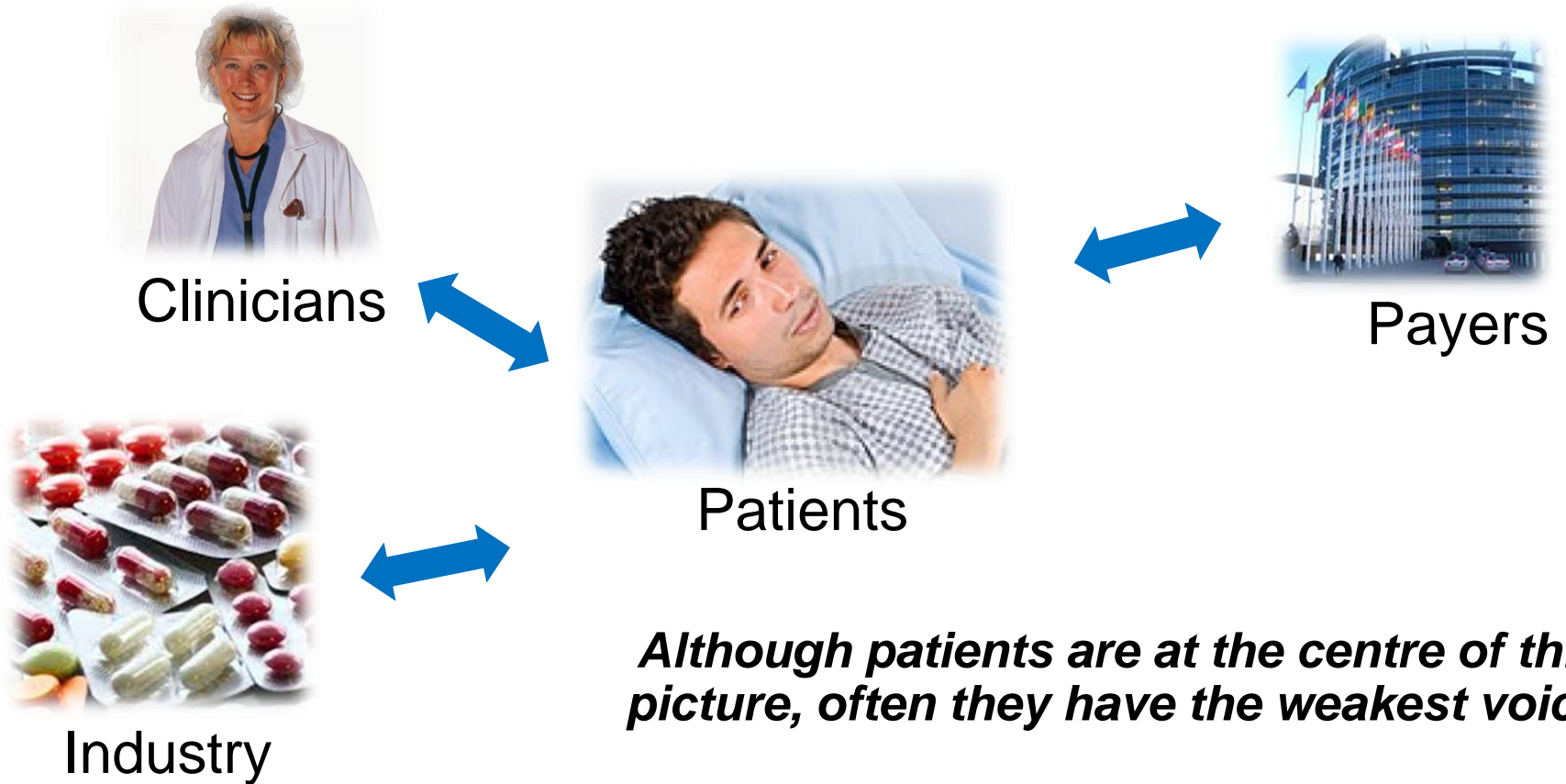
Payers

*We exist in a
complicated healthcare
environment*

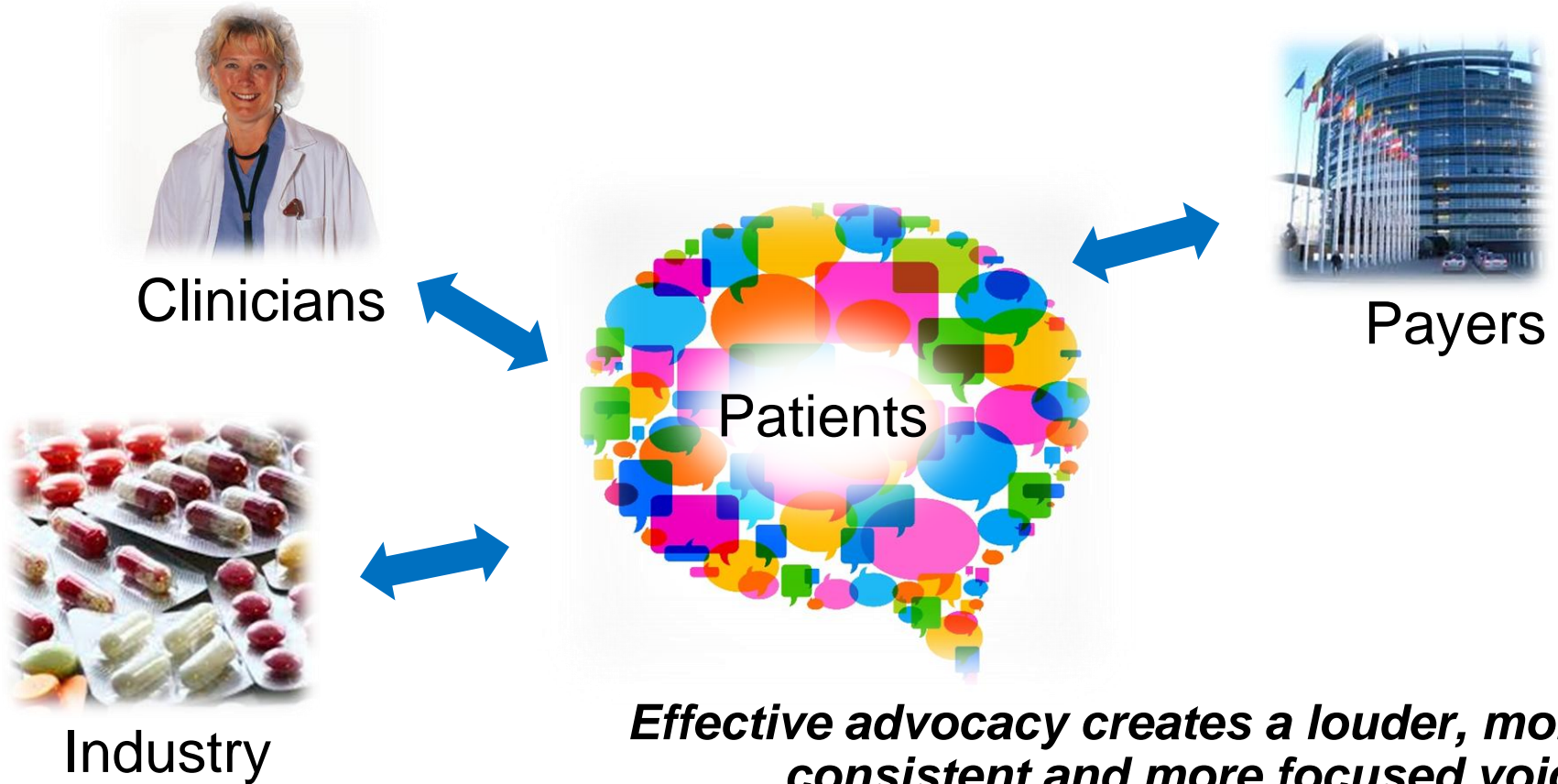


Industry

Patient Advocacy



Patient Advocacy



Patient Advocacy

As advocates for MPN patients, we need to create meaningful, honest and ongoing dialogue with

- **Payers** – “why do you not pay for this here?”
“do you really understand the burden of MPNs?”
- **Clinicians** – “why do you not use this here?”
“why can’t I be on this trial?”
- **Industry** – “why did you discontinue this research?”,
“does it really have to cost that much?”

MPN Advocates Network

This weekend, our goals are:

- To become a truly global network
- To share best practice
- To discuss how we can collaborate to help MPN patients all around the world