



EMP
EUROPEAN
MYELOMA
PLATFORM

patients for patients



‘no policy without patients’

Peter Randløv

Danish Myeloma Association

EMP Board of Directors

Former consulting engineer

MM patient since 1997



EMP
EUROPEAN
MYELOMA
PLATFORM
patients for patients



An example from practice

Current role of the patient organisation
Experience on European level



EMP
EUROPEAN
MYELOMA
PLATFORM

patients for patients



THALIDOMIDE

- 2001 Orphan drug designation
- 2003 Application for MA
- 2008 Marketing Authorisation, MA



EMP
EUROPEAN
MYELOMA
PLATFORM
patients for patients



1st meeting in EMEA

- Common actions needed
- Victims' and Patients Position Paper
- Cooperation between MM associations



EMP
EUROPEAN
MYELOMA
PLATFORM

patients for patients



The Process

- 2005 First steps towards closer cooperation
- Nov. 2005 Guidelines on RMP
- 2006 EMP was formed



EMP
EUROPEAN
MYELOMA
PLATFORM



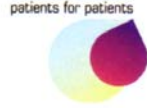
patients for patients

Future Roles

- Informed consent
- Patients' participation in trials
- Centres of expertise
- Reference Networks



EMP
EUROPEAN
MYELOMA
PLATFORM



patients for patients

Future Challenges

- More complexity
- Human resources
- Finances



EMP
EUROPEAN
MYELOMA
PLATFORM



patients for patients

Lessons learned

- International cooperation is needed
- Authorities welcome patients' organisations
- Utilisation of resources



EMP
EUROPEAN
MYELOMA
PLATFORM
patients for patients



Thank you for listening

Husk at elske,
Love while you've got

MENS du tør det.
Love to give.

Husk at leve,
Live while you've got

MENS du gør det.
Life to live.