

Successful collaborations between patient advocates and oncologists

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SUCCESSFUL PATIENT ADVOCACY



**Disease
and Care**

**Systems
Knowledge**

**Advocacy
Tools & best
Practice**

The 3 knowledge pillars of effective Melanoma advocacy

Disease

- Melanoma
- treatments
- disease management
- early detection and follow-up schemes
- genetic predisposition, risk factors and prevention

Systems

Healthcare

- access to Melanoma care: how does my healthcare system work?
- drug development, including regulatory, HTA and reimbursement

Political

- decision-making in healthcare

Research

- how does research work, how to drive specific research?

Advocacy tools

- strategy
- organisation
- communication
- finance
- governance

MPNE experience

- enter patients into clinical trials
- access to new drugs
- 2nd/3rd/ multiple opinions in difficult cases
- side effects
- Melanoma research protocols (letters of support!)
- Melanoma clinical trials protocols

ESMO experience

- first chair who is not an oncologist
- new concept for the patient advocacy track
- patient advocates can now become ESMO members
- contacts with ESMO YOCs (young oncologists)-co-chaired sessions for ESMO2018

Lessons learned

- focus on outcomes, not procedures
- preparation, knowledge and solid argumentation are key
- tackle the problem, not persons
- accept it'll take ages. Then, be surprised how fast things can move once they start rolling.

Thank you

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