



"How do we get the voice of the patient heard?"

Lidia Schapira M.D.
Harvard Medical School
Massachusetts General Hospital



Objectives

- "To provide insights from your research that may inform how advocates can be more effective in providing the patient perspective in the research setting"
- A certain disposition?
Set of skills?
Personal experience?



A shared vision





Research Advocate

- Personality and attributes
- Disposition
- Personal history and experience
- Knowledge base
- Motivation and vision
- Communication and negotiation skills



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A skill set

• Essential Skills

- ☐ Critical thinking
- ☐ Scientific literacy
- ☐ Self-awareness
- ☐ Assertiveness
- ☐ Experience with teamwork
- ☐ Perspective
- ☐ Trustworthiness



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Research Advocate Checklist

- ✓ Prepare for the meeting
- ✓ Meet the researchers
- ✓ Make a contribution
- ✓ Reflect and debrief after the meeting, hold yourself accountable
- ✓ Receive and provide mentorship
- ✓ Provide a clear message back to the patient community



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Recommendations

- Develop metrics to quantify the contribution
- Aim for written recommendations and evaluation
- Establish a curriculum and standards
- Define an ideal performance
- Foster mentoring relationships by identifying and recognizing mentors
- Increase the visibility and expand the role through publications and training
- Educate researchers about the role, funding, training and supervision of research advocates



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Research Advocate Training

- Screening
- Selection – need to draw from diverse populations and interest groups
- Theoretical and experiential learning
- Communication skills, reflection, self-awareness
- Case based learning
- Supervision



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Thank You!
lschapira@mgh.harvard.edu

