#### Patient Perspectives - Cancer Immunotherapy Clinical Trials

Gwen Darien
Director, The Pathways Project
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Concepts and Challenges
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#### Gwen Darien

The following relationships exist related to this presentation:

No Relationships to Disclose

### Patient Perspectives on Clinical Trials

- Subject of much debate and controversy among patients and patient advocates
- Multiple perspectives and values drive debate
- Complex and nuanced issues frame discussion about ethics of clinical trials

# Patient Perspectives on Clinical Trials Framing the discussion

- The inherent tension between research and treatment
- Lack of effective treatment as justification
- Lack of proven efficacy, measurement of benefits

#### Tension between Research and Treatment

- Where does interest of the patient intersect with the needs of science?
- Can the needs of future knowledge through clinical research be reconciled with imperatives of clinical care?

#### Tension between Research and Treatment

- Are there potential benefits for patients participating in clinical trials?
- If not, what is the ethical justification for promoting clinical trials as best treatment option when no other is available?

# Tension between Research and Treatment Intersection of interest and need Reconciling knowledge and care

- Critical scientifically
  - What is the scientific justification for participating in immunotherapy clinical trials
  - How to assess risk and benefit
- Toxicity
- Stuck with the status quo if there are no clinical trials
- On the other hand, should not overpromise and risks must be clearly explained

# Tension between Research and Treatment Intersection of interest and need Reconciling knowledge and care

- Most patients want as much benefit as possible
  - Despite telling patients can't promise benefits,
     lure is still there
- Underlying issue is truly informed consent does it really exist?
  - Consent documents not designed to improve patient understanding

### Tension between Research and Treatment Potential personal benefits Best treatment option?

- Choosing a course of action is almost never a "best" vs. "worst" decision, is a decision among poor options
- Patient weighs: cost, quality of life, location
- Every patient comes with different values, expectations, measure of benefit

# Tension between Research and Treatment Potential personal benefits Best treatment option?

- Answer is to design more meaningful studies
- How to judge meaningful benefit in cancer immunotherapy trials

### Lack of effective treatment as justification

- Central justification for immunotherapy trials is no effective treatment currently exists or treatment is extremely toxic
- When is it ethical to have an immunotherapy trial?