

#### Slide 2

# Presenter Disclosures W. Andrew Faucett (1) The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months: "No relationships to disclose"

#### Slide 3

Objective

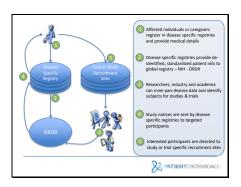
Identify aspects of existing patient-based online communities that may increase research participant enrollment.


# Why Patient Registries?

- Characterize the global patient community
   Connect families to research opportunities
   Provide data for pre-clinical and clinical research
   Facilitate recruitment and reduce enrollment lag



#### Slide 5





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#### Slide 8








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#### Benefits

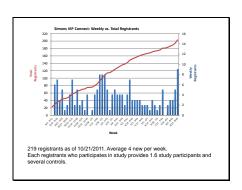
#### Patients

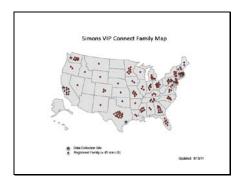
- Ability to organize patient populations for clinical trials &
- Patients can learn from others through survey results
- Raise visibility to patients and researchers
- Complete questionnaires in multiple visits if needed Researchers
- · Learn directly from patients and families
- Ability to recruit for clinical studies & trials pan-disorder
   Gain access to broader pool of clinical candidates
   Interactive maps enable clinical trial site planning

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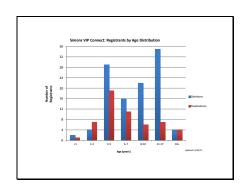
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# Slide 20








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