



*Fund Research, Find A Cure, Support Families.*



## FOP Connection Registry

2016 FOP Friends  
UK Conference & Family Gathering  
Manchester, 21 May 2016

Neal Mantick

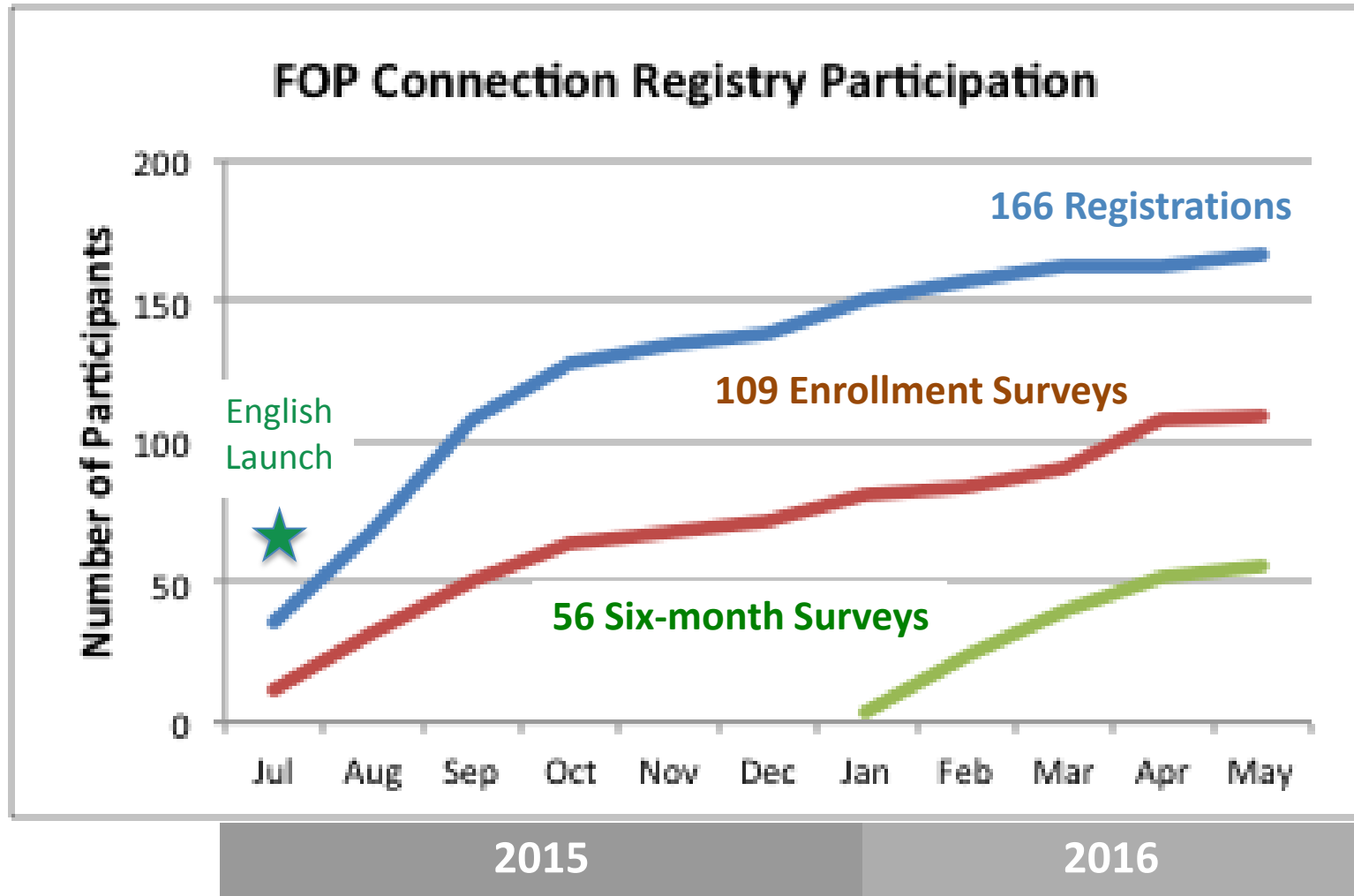
International FOP Association

[registry@fopconnection.org](mailto:registry@fopconnection.org)

# Topics

- ✓ Progress Update
- ✓ Statistics from the Enrollment Surveys
- ✓ Next Steps
- ✓ Questions?

# The Patient Portal had a successful start.



# We are translating the Patient Portal.

## Ongoing Now

- Italian
- Spanish
- Portuguese
- German
- Russian
- French

## Later This Year

- Japanese
- Chinese
- Any others?

# We established an international Patient Advisory Board.

Oliver Collins, Australia

Sharon Kantanie, United States

Jelena Milosevic, Serbia

Marin Wallace, Canada

Nicky Williams, United Kingdom

Roger zum Felde, Germany

# Patient information completes the puzzle.

Pharmaceutical  
Companies

Physicians

Scientific  
Investigators



Patient Advocacy  
Organizations

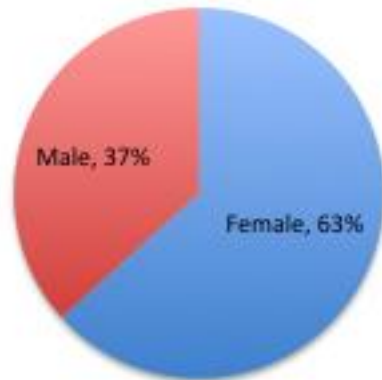
# Participant Demographics: All Registry vs. UK

Population	All Registry (160)	UK (11)
<b>Participant Age</b>		
Average Age (Years)	24.9	16.5
Age Range (Years)	1 – 75	2 – 46
% Minor Children (≤ 17 Years)	35%	55%

# Participant Demographics: All Registry vs. UK

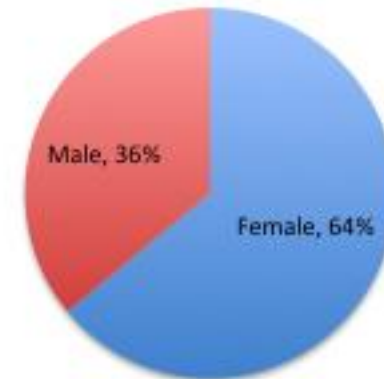
## All Registry (166)

### Participant Gender



## UK (11)

### Participant Gender





**Two scientific posters were accepted for presentation.**



**26-28 May 2016 Edinburgh**

European Conference on Rare Diseases & Orphan Products

The FOP Connection Registry: A Patient Registry Directed by the FOP Community



**Bone Research Society**

Bringing basic and clinical researchers together

28 June – 1 July 2016 Liverpool

The Fibrodysplasia Ossificans Progressiva (FOP)

Connection Registry: patient reports of new bone growth

The Registry is made up of two portals.

## The FOP Connection Registry

✓ **Launched**

**Patient Portal**

**Medical Portal**

# We are now working on the Medical Portal.

- Developing the content (survey questions) and applying the technology
- Creating a governance structure
- Establishing a funding approach

**Alone we are rare,  
together we are strong**

-US National Organization of Rare Disorders

**Thank you!**  
**Questions?**

I will be at the *Meet the Scientists* workshop later today if you would like to review parts of the Registry website or to enroll.