

The OI Research
Collaborative:
Where Researcher and
Community Members
Connect for a Better OI Life



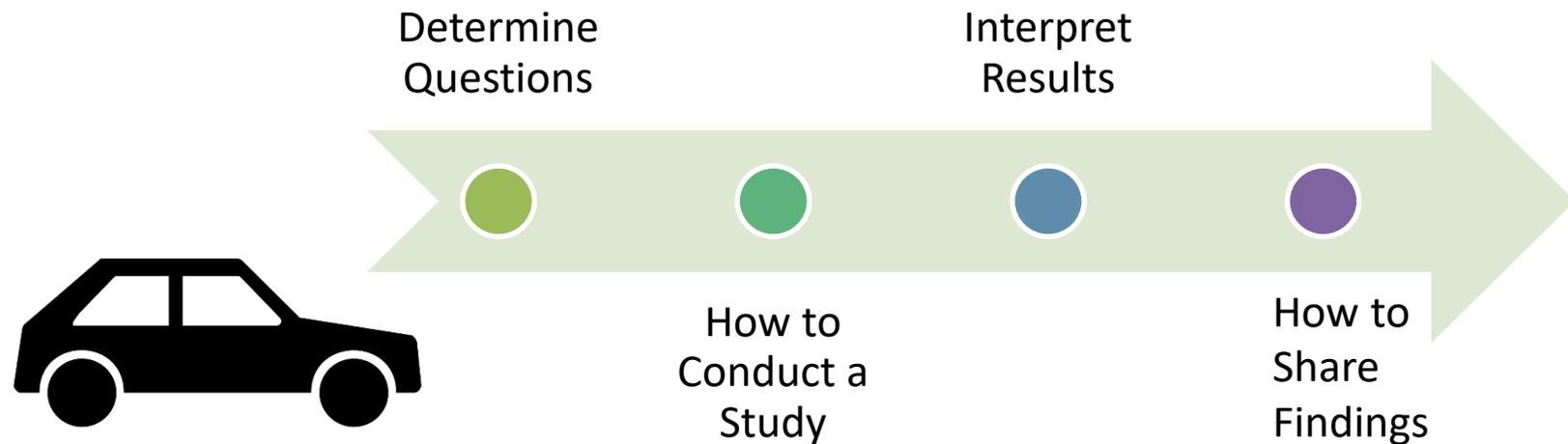
This presentation was funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (14517-OIF).

Overview

1. What is Patient-Centered Outcomes Research (PCOR)?
2. Overview of the OI Foundation's Grant
3. What the OIF is Currently Doing
4. How you can get involved

Overview of PCOR

- In order to provide the best care and information, the OI Community needs to be driving the science.
- Patient Centered Outcomes Research (PCOR) is different from traditional research. Community members are active participants throughout the **entire** research process.



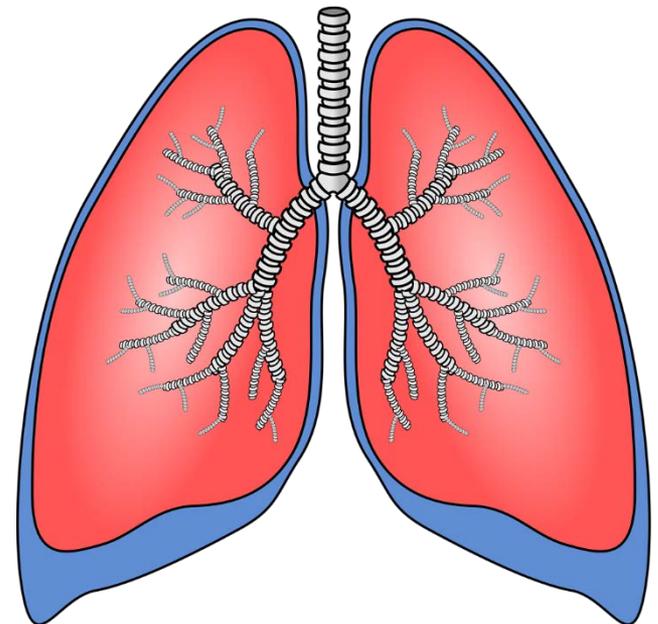
- How to get involved

Managing OI: More than Bones

- OI is a disorder of collagen
- Body has 13 different “organ systems”
Example: Skeletal System, Nervous System
- Virtually every organ system in the body contains collagen

Example: Respiratory system

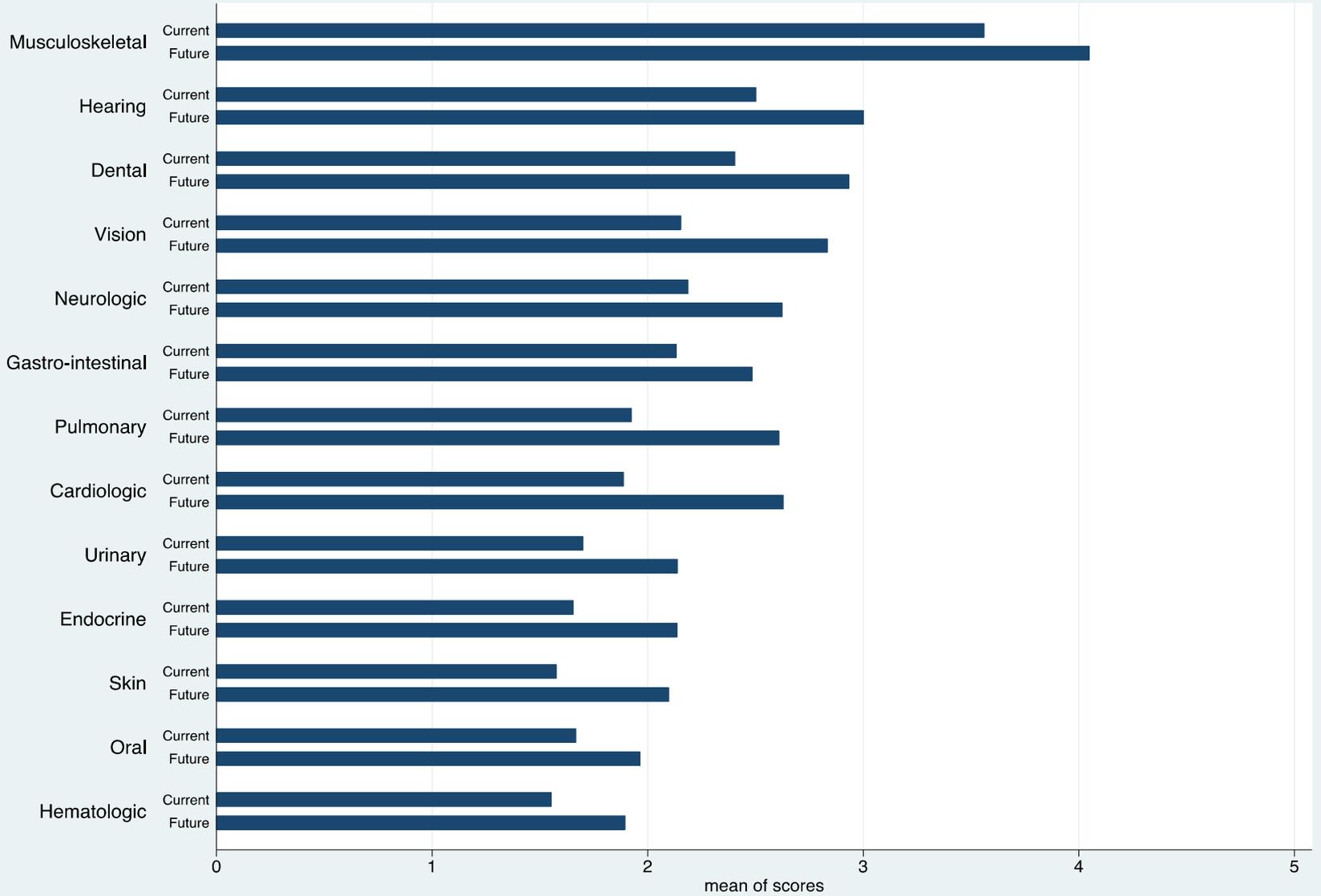
Folkestad L, et al. Mortality and Causes of Death in Patients With Osteogenesis Imperfecta: A Register-Based Nationwide Cohort Study. *J Bone Miner Res.* 2016 Dec;31(12):2159-2166.



2011 OI Foundation Online survey of Adult Health Concerns

- OI community expressed on-going problems and concerns about each and every organ system

Impact on quality of life





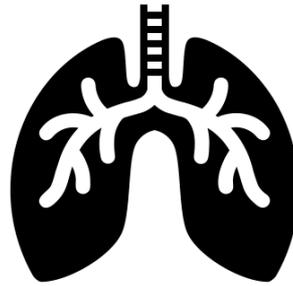
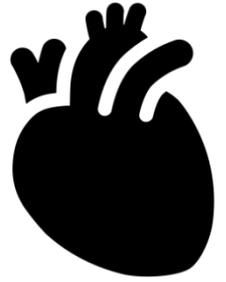
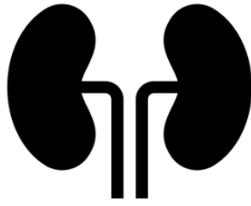
Most Concerning:
Most health
problems were far
more common in
persons with OI
than the general
population

Skin, Urinary, GI

Condition	PREVALENCE			
	ANHI 2011			US Population
	Mild (%)	Mod (%)	Severe (%)	
Bruises	39	31	13	18% (12-55%)
Dry Skin	35	34	30	1.5-3.0%
Incontinence	8	10	8	37%
Kidney or Bladder Stones	9	13	10	5%
Diabetes/High Blood Sugar	11	12	9	9 - 11.5%
Low Thyroid Function	8	9	10	5%
Constipation	26	27	28	15-20%
Hemorrhoids	17	16	13	< 4%
Reflux/Heartburn	34	34	38	3 - 7%

Cardiac and Pulmonary

Condition	PREVALENCE			
	ANHI 2011			US Population
	Mild (%)	Mod (%)	Severe (%)	
Blood Vessel Problems (rupture, aneurysm)	5	5	5	1.8 - 3.2%
Coronary Artery Disease	4	5	2	6 - 7%
Heart Attack	9	6	4	3-4%
Heart Valve	8	6	6	1.8-2.5%
High Blood Pressure	38	33	39	23 - 25%
High Cholesterol	27	26	20	24 - 27%
Strokes	5	4	5	2.5-4%
Cough	16	18	13	12%
Shortness of Breath	27	26	30	10-18% (under 65); 30+% (>65 years)
Sleep Apnea	14	14	16	< 5%
Wheezing (Asthma)	16	13	16	8%

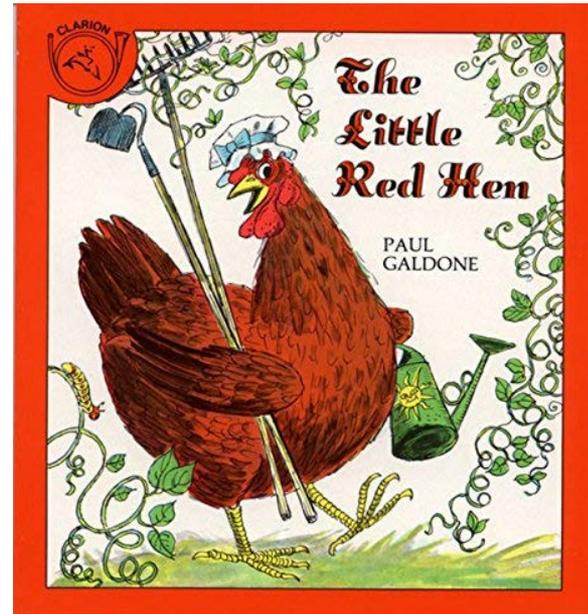


Participants were especially concerned about their future health status in regards to their heart, lungs, vision, endocrine function, and digestive system.



Numerous surveys, focus groups, etc. led to the conclusion that, given the complexity of OI, true understanding of the disorder, and how it changes over time, requires engaging the ENTIRE community

- And, like the fairy tale, the Little Red Hen, we needed to do it ourselves



Which led us to...

**Apply for and WIN a
Patient-Centered
Outcomes Research
Institute**

***Eugene Washington
Engagement Award***



Our Grant

**Improving Patient-Centered Outcomes:
Expanding Engagement of the Osteogenesis
Imperfecta Community**

2 years

Launched on June 1, 2019



What is Patient-Centered Outcomes Research?

Research driven by the OI
Community's needs and
concerns

OI Community included in
entire research process

Results help your doctors address
the concerns that you feel are
most important to you

Patient-Centered Outcomes Research Engages the Entire Community

Parents

People with OI



Family Members and Caregivers



Doctors and Researchers with an interest in
OI

Project Overview



Provide patients, caregivers, and clinicians better information to make important medical decisions.

Develop a coalition of community members and medical professionals who will direct new and inclusive OI research.

Engage the entire OI community in defining important aspects living with OI across the lifespan.

Making Research a Two-Way Street

Old Research Priorities



New Research Priorities



Our Project

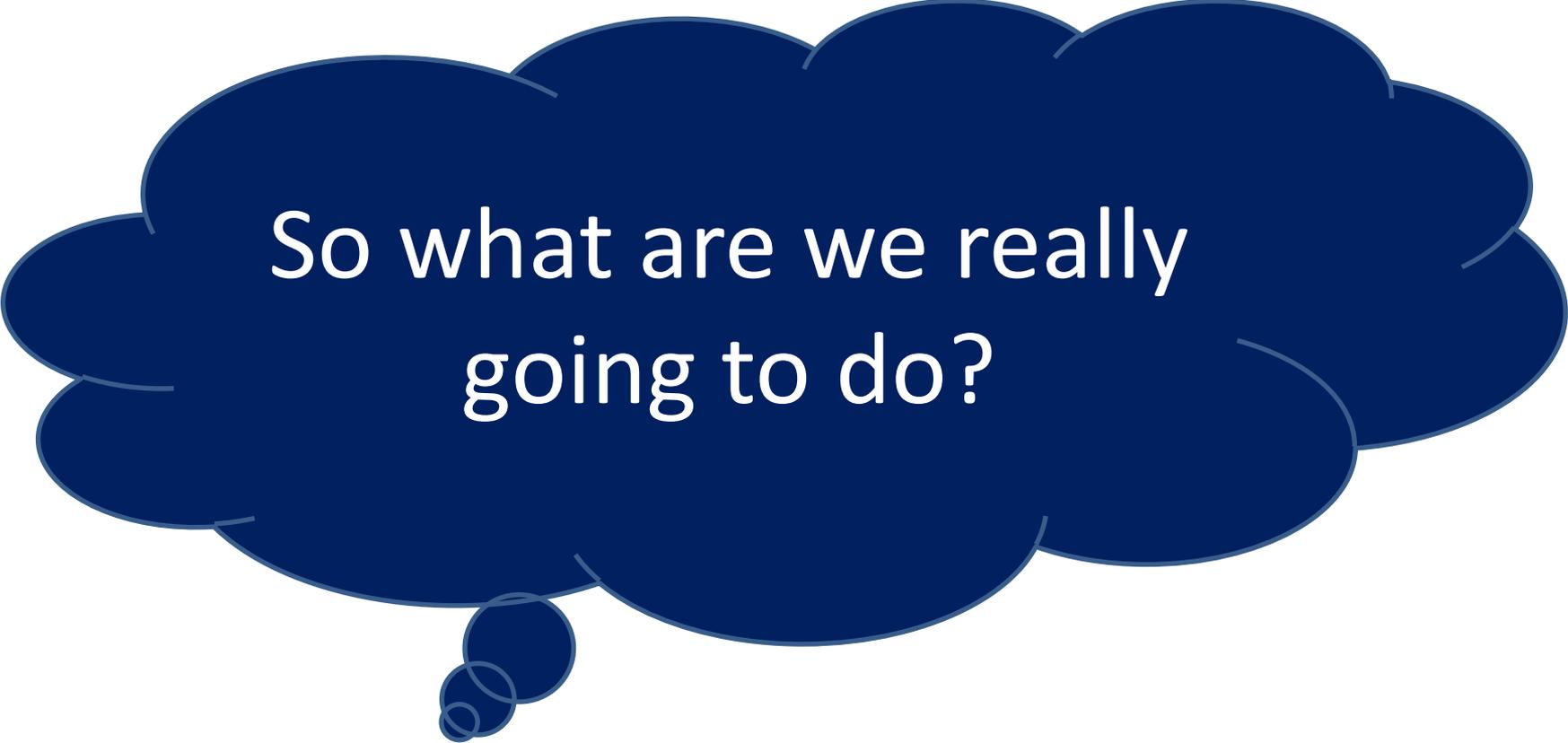
Short term:

Collaborate with the entire OI Community, including researchers and doctors, to increase participation of the Community in research

Long Term

Maintain a lasting collaboration with the entire OI Community that leads to better and up to date information with which to make important medical decisions

OK...

A large, dark blue thought bubble with a white question inside. The bubble has a soft, irregular shape with a thin white outline. At the bottom left, there are three smaller, overlapping circles of the same color, suggesting a trail or a connection to another thought.

So what are we really
going to do?

What Are We Doing Right Now?

- Take every opportunity to inform and engage the entire OI community
- You're the experts! We want to learn from you to better understand the challenges of living with OI to improve research, care, and support

Regional Meetings

OIF Newsletters
(Research Update coming soon!)

Fundraising Appeals

Dedicated OI PCOR website

National Meeting

OIF Scientific Meeting

Listen... Recruit ... Practice



- Seek feedback from all events
- Recruit community members to sign up for the OI Patient Registry (a way to communicate with you!)
- Recruit and educate a team of patients/caregivers/clinicians /researchers willing to help guide this work
- Use the OI Patient Registry to begin to explore questions of interest to the community

Tip of the Iceberg

This project will set us up to apply for more grant money to fund projects the OI community cares about

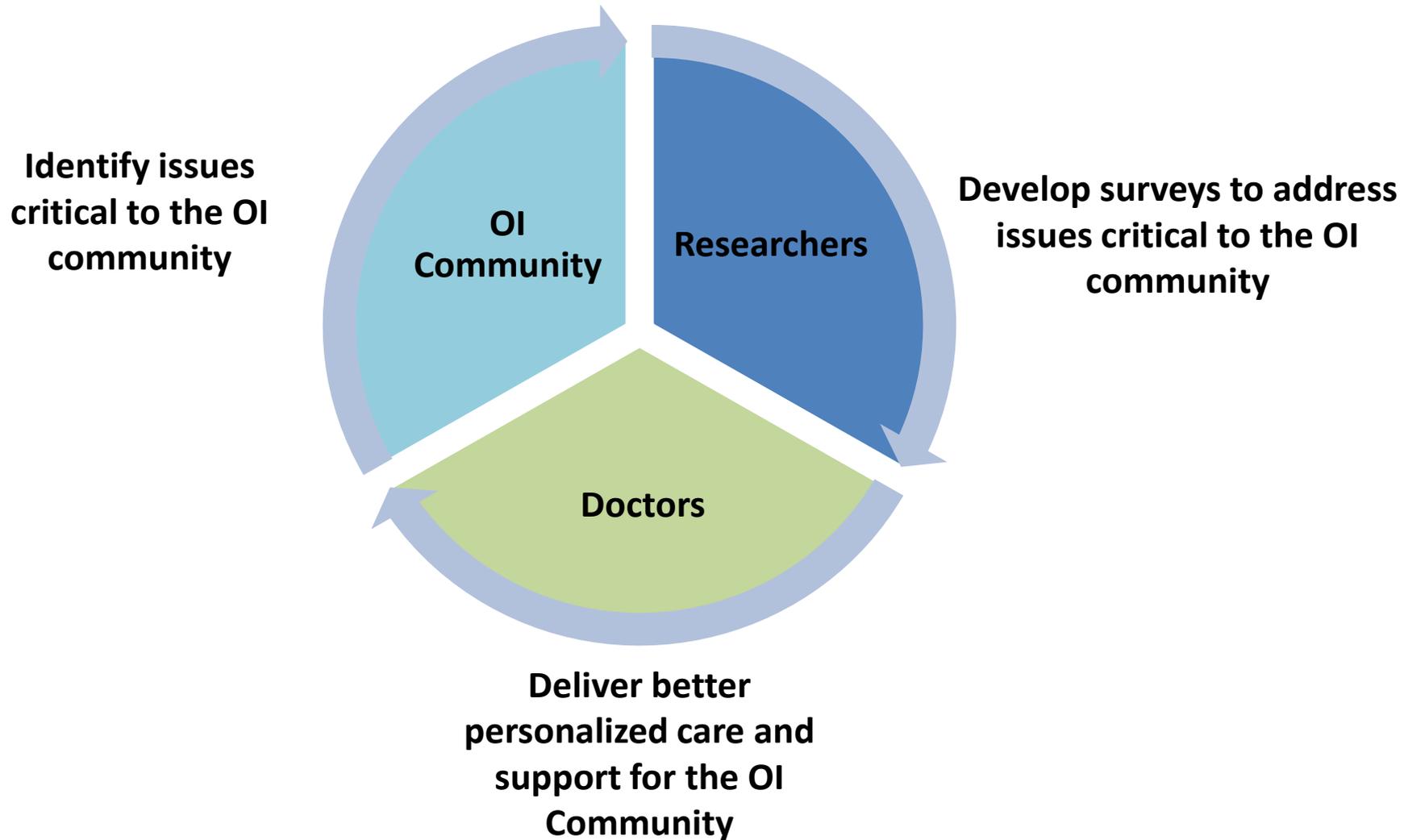


Long Term “Pie in the Sky” Goal

A lasting collaboration with the entire OI Community that **leads to better and up-to-date information** with which to make important medical decisions across the lifecycle.



Flow of Collaboration



What does Patient-Centered Outcomes Research mean to a person with OI?

Researchers are better able to understand aspects of living with OI that they hadn't before



More research can improve the field of OI care and support

What does Patient-Centered Outcomes Research mean to a parent of a child with OI?



Parent expertise is considered in research and clinical decision making



Research can improve the field of OI care and support for your child



Action Items:

Please Consider Working With Us...

- Look for our articles in Breakthrough
- Follow our updates on our dedicated website (coming soon!)
- Sign up for OI Patient Registry

The most important members ... you!



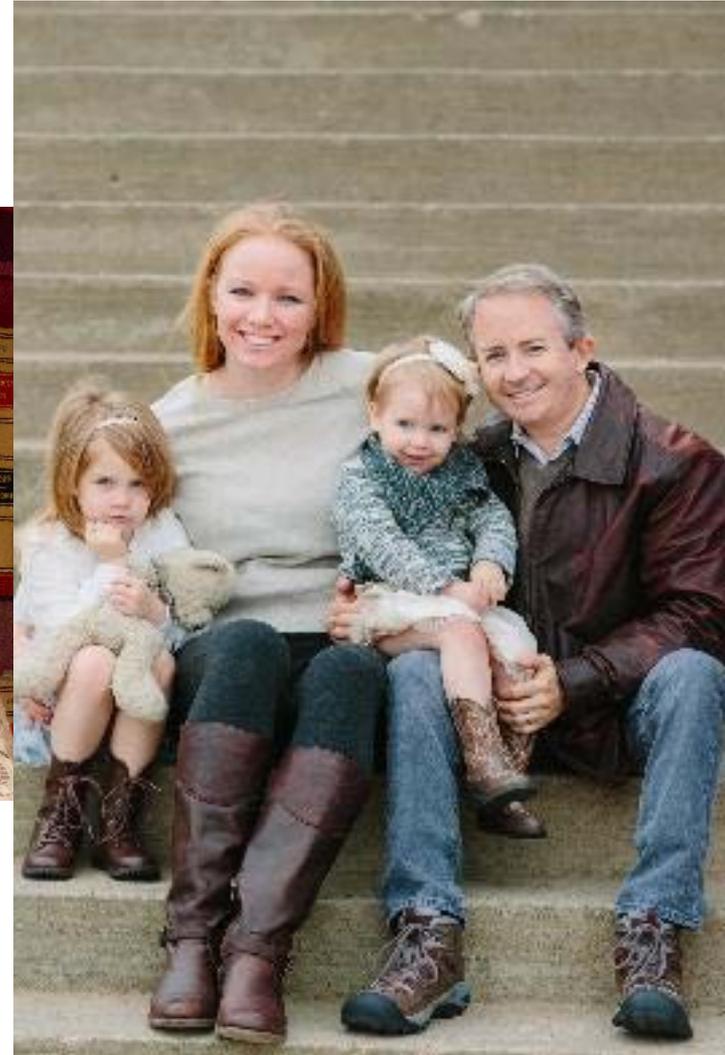
Committee Leadership



Mark Birdwhistell



Michelle Duprey



Cameron Penn

Additional Steering Committee members



Tracy Hart



Laura Tosi



Bryce Reeve PhD

Discussion Topics

Do you feel that researchers understand about living with OI?

Do you feel that current research is relevant to you?

Do you talk about your worries to your doctors and find that they're unable to locate any research that addresses your concern?

Do you feel disconnected from the research being done on OI?

Have you heard of Patient-Centered Outcomes Research?



Thank you!

For any questions, please contact Tracy Hart at thart@oif.org or Rachel Stivers at rstivers@oif.org.