OI Foundation Project, Improving Patient-Centered Outcomes: Expanding Engagement of the Osteogenesis Imperfecta Community, Approved for Supplemental Funding Award

Gaithersburg, MD (August 14, 2020) – The Osteogenesis Imperfecta Foundation is excited to announce that supplemental funding has been approved for the Improving Patient-Centered Outcomes: Expanding Engagement of the Osteogenesis Imperfecta Community project to include investigating the impact of the COVID-19 pandemic on the osteogenesis imperfecta community. This important project advances the collaboration of the OI Foundation (Tracy Hart, CEO, Lead) and Co-Leads Dr. Laura Tosi, Director, Bone Health Program, Children’s National Hospital and Dr. Bryce Reeve, Director, Center for Health Measurement, Duke University. The goals of the supplemental funding award are to assist the rare bone disease community in developing COVID-19 content and outreach, expand the OI PCOR toolkit to include COVID-19-specific resources, expand OI clinic outreach to disseminate content on COVID-19, and create and disseminate OI-relevant COVID-19 content.

In 2019, the OI Foundation was approved for a two-year award for a project on Improving Patient-Centered Outcomes: Expanding Engagement of the Osteogenesis Imperfecta Community through the Eugene Washington PCORI Engagement Awards (Engagement Awards) program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). PCORI is an independent, nonprofit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work. The aims of the project are to bring together stakeholder groups on equal footing to identify and fill knowledge gaps, prioritize questions to be addressed with research, and return discoveries to the entire OI community to support collaborative decision-making and improve health outcomes.

Read more about this project and the accomplished work to date at www.oif.org/pcor.

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