Using the ECHO Model® to Expand Professional Learning Opportunities for Osteogenesis Imperfecta

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The Landscape of OI

Few clinicians know how to properly diagnose and treat rare bone diseases like osteogenesis imperfecta. Osteogenesis imperfecta (OI), sometimes known as "brittle bone disease, is a genetic bone disorder characterized by fragile bones that break easily.

While the Osteogenesis Imperfecta Foundation (OIF) and the Brittle Bone Disorders Consortium (BBDC) support research on this rare disorder, patients with OI still struggle to find doctors and clinicians with experience treating the condition. Each year, hundreds of community members reach out to the OIF asking for referrals for providers with OI experience; however, demand from OI community members for proper care outweighs the supply of knowledgeable clinicians.

To help increase knowledge about OI amongst providers, in 2020 the OIF partnered with Project ECHO® (Extension for Community Healthcare Outcomes) to create a virtual professional education program for medical professionals interested in learning more about OI. The OIF, along with the Rare Bone Disease Alliance, had previously partnered with Project ECHO® in 2019 to launch the successful Rare Bone Disease TeleECHO Clinic Series, a free monthly virtual meetings that provide medical education and continuing medical education (CME) credits for medical providers. The Rare Bone Disease ECHO focuses on improving the diagnosis and treatment of rare bone diseases and has reached thousands of providers in dozens of countries in its three-year history. Encouraged by the success of this sibling program, the OI ECHO aimed to also provide virtual educational opportunities to improve patient outcomes for people with OI.

ECHO Session Format

The ECHO Model ® reduces barriers to participate and encourages medical professional learning in the OI TeleECHO Clinic Series. In every session, expert medical faculty and guest speakers deliver a didactic presentation on diagnosing or treating OI, group discussions, and then followed by participant-led case presentations. Overall, ECHO sessions are not webinars; the ECHO model encourages attendee participation and understands that most of the learning happens during discussions and case presentations in addition to didactic presentations. Through the partnership with Project ECHO®, attendees can receive AMA PRA Category 1 Credits™ for attending the live sessions.

All the sessions are held as regularly scheduled Zoom meetings, and participants can register for each of the year's upcoming sessions on www.OIF.org, respectively. To promote these sessions, the OIF sends out email announcements to targeted groups, posts fliers with relevant professional societies like the American Society for Bone Mineral Research (ASBMR) . and uses word of mouth from past attendees and speakers. The OI ECHO's year program meanwhile averaged 57 attendees in its 12 sessions from August 2020 to July 2021.

Medical Faculty, Presentation Topics, and Speakers

Faculty

The OI ECHO has a small faculty of medical professionals with complimentary expertise, and they created the initial agenda with all the session topics and guest speakers. These faculty take on the leadership role in developing the program's educational content, deliver their own main presentations, and serve as host when guest speakers are invited to present. In selecting the main presentation themes, the faculty selected topics that are essential to properly diagnosing and treating OI and then invite highly experienced and published researchers and clinicians to give each main presentation, which often accounts for about half of each session. Furthermore, all the faculty and speakers are members at participating clinical centers in the BBDC.

For the OI ECHO, the medical faculty include:

- Frank Rauch, MD, (Chair) Shriner's Hospital for Children – Canada
- Jeanne M. Franzone, MD, Nemours/A.I. duPont Hospital for Children
- Sandesh C.S. Nagamani, MD, Baylor College of Medicine.

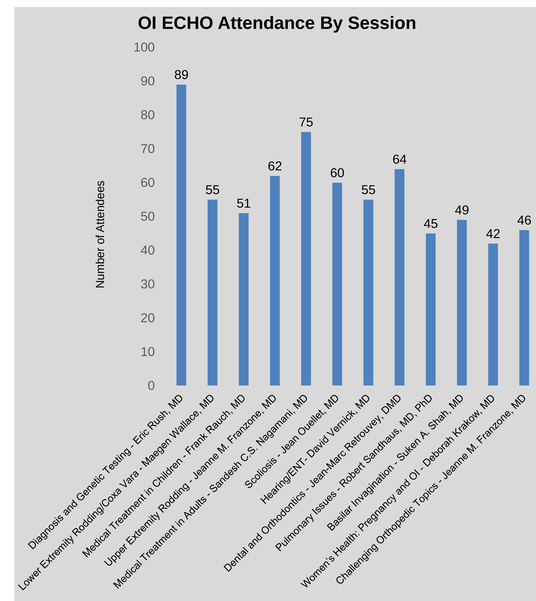
OI TeleECHO Agenda 2020-2021

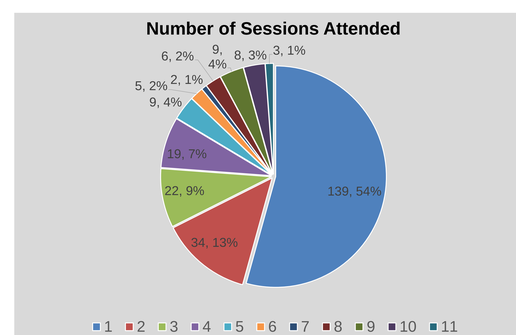
Session Date	Session Title and Speaker
10/14/20	Diagnosis and Genetic Testing – Eric Rush, MD
11/11/20	Lower Extremity Rodding/Coxa Vara - Maegen Wallace, MD
12/9/20	Medical Treatment in Children - Frank Rauch, MD
1/13/21	Upper Extremity Rodding - Jeanne M. Franzone, MD
2/10/21	Medical Treatment in Adults - Sandesh C.S. Nagamani, MD
3/10/21	Scoliosis - Jean Ouellet, MD
4/14/21	Hearing/ENT- David Vernick, MD
5/12/21	Dental and Orthodontics - Jean-Marc Retrouvey, DMD
06/09/21	Pulmonary Issues - Robert Sandhaus, MD, PhD
7/14/21	Basilar Invagination - Suken A. Shah, MD
8/11/21	Women's Health: Pregnancy and OI - Deborah Krakow, MD
9/8/21	Challenging Orthopedic Topics - Jeanne M. Franzone, MD

OI ECHO Attendance

In its 12 monthly sessions between October 2020 to September 2021, the OI ECHO had a total attendance of 693, with an average attendance per session of 57. Monthly sessions were held on the second Wednesday of each month at 3:00 PM Eastern Time.

Zoom meetings makes it difficult to know the exact number of unique attendees from session to session. Some logged in using different emails or names each time, used phones, or inconsistently completed the attendance forms. Despite these limitations, 257 unique emails participated in the 12 combined sessions, which the OIF took as an approximate substitute for unique participants. Of those unique emails, 54% (139) attended only one session, and the remaining attended multiple sessions. Within those returning emails, 24% of them (59) attended at least 4 sessions.

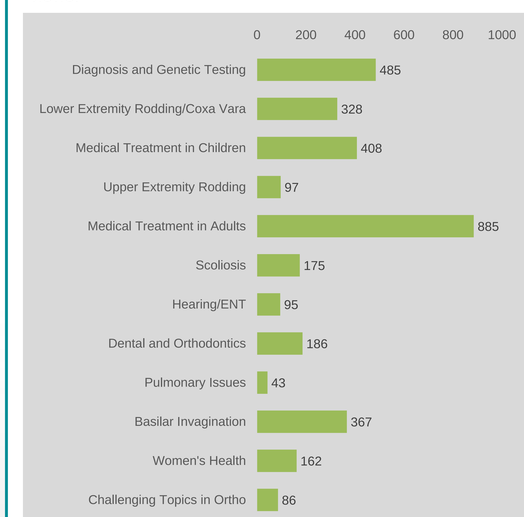




Session Recordings

YouTube Views

The OI ECHO Clinic Series has also recorded material that is publicly accessible on YouTube. To protect patient confidentiality, only the main presentations are uploaded to the OIF's YouTube Channel, and all patient information is de-identified. Also, links to these videos are available on the OIF's website and on the National Institute's of Health's (NIH) Center for Leading Innovation and Collaboration (CLIC) website. As of January 27, 2023, these recordings have had over 3317 total YouTube views. Below is a chart of each session's YouTube views.



Conclusion

Overall, the OI ECHO's first full year was a success. Hundreds of medical professionals participated in live sessions with BBDC affiliated speakers, dozens were able to present patient cases for feedback, and thousands more watched recordings online. However, the program still has room to improve. The most engaged participants were physicians who already had significant OI experience, and early career providers or physicians with less OI experience often only attended one session. Also, faculty and OIF staff had difficulty finding relevant case presentations for each session, a central part of Project ECHO®'s learning model. Despite these challenges, the OI ECHO provided medical professional education by sharing BBDC research in a format that encouraged clinician participation and led to improved patient outcomes.

The OIF plans to continue the OI ECHO program in 2023 with more sessions that supplement the existing catalogue of topics.