“I had not anticipated how wonderful it would be for me to meet and share experiences with other families (at the OIF Conference). I arrived home absolutely inspired. I was infused with hope, support, and a new sense of community that one could only get from attending the OIF Conference in person.”

A Conference to Remember

The 2018 OIF National Conference, themed EXPLORE, gathered over 650 attendees and 50 speakers for a busy, fun-filled, and memorable weekend in Baltimore, Maryland! The attendees of this summer’s conference represented seven countries and nearly forty US states. New and old friends were able to participate in a full line-up of activities; one-on-one medical consultations, informational sessions, age and gender specific forums, the National Unbreakable Spirit® Walk-n-Wheel, the OI Career Expo, the first-ever OIF Art Showcase, the OIF National Conference Talent Show, the Closing Dinner, and more!

National Unbreakable Spirit® Walk-n-Wheel Baltimore
On the evening of Thursday, July 12th, 300 members of the OI community took Baltimore’s Inner Harbor by storm, kicking off the OIF National Conference with the National Unbreakable Spirit® Walk-n-Wheel! Participants walked and wheeled from the Renaissance Baltimore Harborplace Hotel to the National Aquarium, where they enjoyed exclusive after-hours entry to one of the world’s best aquariums. Thank you to Mereo Biopharma for sponsoring the finish line goodie bags, the Degna Spoldi Family Foundation for sponsoring the walk-n-wheel t-shirts, University of Kentucky Healthcare for cheering participants along, and Chick-fil-A for donating chicken sandwiches to all participants!

Congratulations to the Kamal & Coughlin Canucks, the top fundraising team; Sophia Kamal, the top youth fundraiser; former OIF Board President Mark Birdwhistell, the top adult fundraiser; and the Wishbone Walkabouts, the largest Walk-n-Wheel team (21 members)! Together, we raised more than $110,000 for the OI Foundation! We cannot wait to see the turnout at the 2020 National Unbreakable Spirit® Walk-n-Wheel on Thursday, July 9th in Omaha, Nebraska!

OIF Advocacy Day
On the morning of Thursday, July 12th, two dozen OIF Conference attendees participated in an Advocacy Day trip to visit lawmakers on Capitol Hill. The attendees, including OIF Board Members and advocates, met with their Senators and House members to discuss how OI has affected them and the ways in which Congress can help promote critical research. The OIF’s message focused on the need for strong funding of NIH-supported OI research, particularly the Brittle Bone Disorders Rare Disease Clinical Research Consortium. The lawmakers and their staff were impressed with the dedication of the advocates and supportive of our request to maintain strong research funding. Thank you to Kyle Mulroy, Ross Airington, Debbie DuCey, and Eric Gould for their work preparing for OIF Advocacy Day!
The largest OIF Medical Consultation Day ever began early on Friday, July 13th - the first full day of conference. Over thirty medical professionals provided 250 one-on-one meetings with Conference attendees to answer questions related to the following fields: adult health, orthopedics, genetics, pediatrics, physical therapy, dental, hearing, respiratory, women’s health, and psychosocial health. For many conference attendees, this opportunity was an encouraging beginning to an informative and unique weekend.

The official Conference program opened with a formal welcome from OIF CEO Tracy Hart, OIF Board of Directors President Ken Gudek, and OIF Medical Advisory Council (MAC) Chair Dr. Francis Glorieux at the OIF National Conference Opening Session. Following the opening remarks and a warm welcome to Baltimore, Tracy, Ken, and Dr. Glorieux introduced OIF Board Member Jacinta Whyte, who is leading the relaunch of the Canadian OI Society (COIS) through a partnership with the OI Foundation. Stay tuned for more information about the COIS and Canadian-based services available to the OI community.

Shifting from welcome announcements to the keynote message, OIF Board Member and Former US Paralympian Dr. Kara Ayers introduced the Conference keynote speaker, US Paralympic Gold Medalist McKenzie Coan. McKenzie, a recent graduate of Loyola University Maryland, shared her passion for swimming and exploring new cities, and spoke about how previous OIF Conferences helped to shape her childhood and teenage years, creating lifelong memories and friendships. At the end of the Opening Session, OI community member Jon Reed reviewed the features of a new and exciting tool that he developed specifically for this conference - a mobile phone app! Downloaded by over half of the conference attendees, the OIF Conference app helped attendees quickly navigate the conference program and the meeting space.

Immediately following the Opening Session, the OIF Career Expo gave Conference attendees the opportunity to network, connect, and learn from fellow OI community members in many different professions. The first day of conference concluded with the fantastic OIF Talent Show, featuring more than twenty of the OI Community’s most talented youth and young adults. Thank you to Suzanne Richard for organizing and hosting this much-appreciated event.
The information sessions on the second day of conference covered a wide variety of clinical topics associated with the diagnosis, treatment, and management of OI in children and adults. The Plenary Session began with the presentation of the Thelma Clack Award to former OIF Board President Mark Birdwhistell for his outstanding commitment to the OI community. Dr. Francis Glorieux and Dr. Brendan Lee then gave updates on the studies and status of the Brittle Bone Disorders Consortium (BBDC). They introduced the principal investigators (PIs) of each clinical site, which led to the introduction of a mini-lecture on the spine and scoliosis, presented by Dr. Suken Shah of Nemours/A.I. DuPont Hospital.

Attendees divided to attend Physician Panel Sessions for pediatric or adult health issues. Both pediatric and adult physician panels addressed topics such as managing bone health, muscle and joint strength, pharmacological treatments, respiratory health, and general health topics. These were the most popular sessions among attendees at the Conference.

Speakers and medical consultants were available to answer questions during Physician Q&A Roundtables (also referred to as Curbside Consultations), where attendees had the opportunity to sit and eat lunch with OI specialists. After the lunch break, attendees returned to learn more about clinical topics in two rounds of afternoon breakout sessions - the OI Youth Empowered and Proud (OI YEP) Forum, and the Mild OI Forum. At the end of a full day of information sessions, a special edition Plenary Session gathered attendees to discuss approaches to managing pain and fatigue in OI.

Day 2 concluded with an extraordinary concert performance starring the National Public Radio (NPR) 2016 Tiny Desk Contest Winner Gaelynn Lea. Gaelynn performed original vocal and violin arrangements for two hours, which echoed throughout the meeting space. After her performance, Gaelynn answered questions, signed albums, and took pictures with conference attendees. For more information about Gaelynn’s story and her current tour, please visit violinscratches.com.
OIF NATIONAL CONFERENCE - DAY THREE

The State of the OI Foundation Plenary Session kicked off the last day of OIF Conference. During this session, the 2018 President’s Award was presented to Tracy Mulroy for her efforts in establishing the Jamie Kendall Fund, which is the first OI community-directed and community-funded research initiative. OIF CEO Tracy Hart and OIF Board President Ken Gudek then gave an update on the OIF’s strategic direction and activities, and explained the OIF’s goals of implementing regional councils. During this Plenary Session, the President of the OI Federation of Europe (OIFE), Ingunn Westerheim, presented an update on the activities and research goals of the OIFE, and discussed how OI-related associations across the globe are working together to advance programs and research. OIF Program Services Director Petra Harvey then reviewed the results of the recent OIF Program Services Survey and discussed a few approaches to addressing the informational needs of the OI community. Overall, this session emphasized the collaboration of local and global OI communities because “OI knows no borders.”

Immediately following the Plenary Session, conference attendees divided into two Expert Panel Sessions – a Dental Forum and the Physical Therapy Forum. Drs. Retrouvey, Hazboun Zahr, and Ricker spoke on pertinent issues in the Dental Forum. Their talks covered multiple dental manifestations of OI, including dentinogenesis imperfecta (DI), abnormal dental development, orthognathic issues, and more. The speakers of the Physical Therapy Forum- Beth Jacks, Reenee Donohoe, Karen Josefyk, Frances Baratta-Ziska, and Christopher Joseph- discussed the key principles of recovering from injuries or surgeries, and strategies for exercise and fitness.

The first-ever OIF Art Showcase, organized by longtime volunteer Ann Marie Geiger, was open during the lunchbreak for Conference attendees to enjoy paintings, photographs, sculptures, and other artwork created by OI community members.

Breakout sessions reconvened after lunch to discuss tips on adjusting well during major life transitions, strategies for independent living, achieving optimal health through nutrition, and implementing 504 and IEP plans in schools. The afternoon program schedule also provided Women and Men’s Wellness Forums, where they discussed gender-specific medical and social topics.

The Closing Dinner and Dance celebrated the new friendships and memories formed by the Unbreakable Spirit® community with three hours of music, food, and dancing.

On behalf of the OIF Board of Directors and Staff, we would like to thank the medical consultants, speakers, volunteers, and participants who contributed to the success of the 2018 OIF National Conference! A special thank you to Dr. Mahim Jain of Kennedy Krieger Institute, who served as the on-call/emergency first aid contact during the conference; and to the many speakers, planning committees, facilitators, and volunteers who not only made careful preparations to present, but also offered their skills, knowledge, and resources to attendees beyond the weekend. This Conference certainly proved to be one to remember!

We hope you will be able to join us at future OIF programs and events. Visit the OIF online calendar, website, and social media pages to stay up-to-date on events near you!

We hope to see you July 9-12, 2020 at the next OIF National Conference in Omaha, Nebraska!
Thank You to Our Sponsors!

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We can’t wait to see you in Omaha, NE!

OIF National Conference // July 9-12, 2020