## FOSTEO's Wishbone Day 2023 Celebration

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By Téa La



Children, young people and families of the FOSTEO community, and the passionate committee behind Wishbone Day 2023 celebrations in Jakarta, Indonesia.

<u>Wishbone Day</u> (WBD) celebration with FOSTEO has once again kicked off with success after being put on-hold since 2018!

WBD is an annual awareness-raising day for the international Osteogenesis Imperfecta (OI) Community, and is celebrated every year on 6 May. Members of FOSTEO, the Indonesian OI community, travelled from as far away as East Java to attend a day of celebration in Jakarta, which was supported by <u>CLAN</u> (Caring & Living As Neighbours) and Yayasan Kesehatan Anak Global (YKAG).

This year 28 families gathered together on Saturday 21 May to strengthen the community's bond in the spirit – and colour! – of WBD. The event was held at RS Pondok Indah Hospital in a spacious outdoor garden next to a community playground. Many passers-by could observe the sea of yellow-clothed people, yellow cupcakes, and yellow decorations. There was an education seminar for parents and a Q&A session with special guests Prof. Aman Pulungan and Dr. Dana Prihadi; fun painting class for children; and a sharing session led by six parents of children living with OI. The education seminar focused on valuable knowledge related to clinical aspects of OI, including holistic management, essential medicines, and tips for enjoying a happy and healthy life with OI. It was a great opportunity for families to learn more about OI, share their experiences and motivate one another.

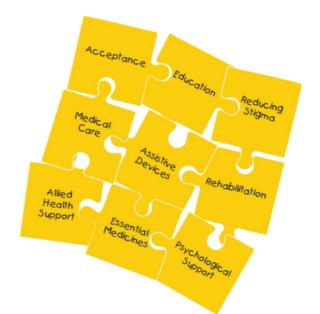




Families left the event with smiles on their faces and an education booklet in hand. The booklet was developed by the team at YKAG and CLAN. Education resources help young people, families, and communities living with chronic health conditions optimise their self-management and quality of life, and achieve their fullest potential. Included in the education booklet was CLAN's OI Child-Friendly Rights Flyer that was launched on WBD as part of collaborative celebrations with the international OI community. It is available in English, Indonesian and Korean languages on CLAN's website. The flyer supports OI advocacy efforts and helps children and young people understand their basic human rights as declared under the United Nations Convention on the Rights of the Child. We extend our warmest thanks to the passionate partners (seen below) involved with the flyer who are committed to engaging in collective advocacy efforts to highlight and protect the rights of #EVERYchild living with OI.



Indonesian OI Education Booklet given to families along with a goodie bag.



Puzzle pieces from CLAN's OI Child-Friendly Rights Flyer.



<sup>1</sup>CLAN (Caring & Living As Neighbours) is an Australian non-government organisation committed to equity for children and young people living with OI and other non-communicable diseases (NCDs) in low- and middle-income countries (LMICs). Families CLAN works with consistently request collaborative focus around five key pillars to help their children enjoy the highest quality of life possible. These five pillars are the intellectual property of CLAN. Further information about CLAN's community development approach is available at www.clanchildhealth.org. For more information on the United Nations Convention on the Rights of the Child (UNCRC) please visit www.unicef.org/crc References: Ragen, J. (2022) The Risk of Good Intentions: Navigating outcomes for people with disability. Sydney University. Sydney, Australia. Wishy Logo on this document is credited to Wishbone Day. The image is available at www.wishboneday.com FOSTEO has grown in number and activities since their founding in 2012. They now have over 200 members living with OI across Indonesia. The community fosters a supportive and encouraging environment for new and old members alike, supporting them to come together and share their experiences. FOSTEO has a long history of enjoying expertly organised community events – many of which gained national TV coverage. However, financial burdens and the unprecedented COVID-19 pandemic had disrupted these annual activities for 5 years. CLAN and YKAG's teams were so happy to see families once again gather in liveliness and reinvigorate the community's spirit.



Fun painting session for children.

"Why is Wishbone Day Important? Because awareness makes a difference."

This is the motto for WBD. The spirit of WBD is an opportunity to privilege the voices of OI communities across the globe and join with them in celebration of the achievements of all people living with OI. Awareness of OI in the wider community creates much-needed space to have these important discussions at a whole of society level and invite others to get involved in driving practical changes for people living with OI so we all enjoy our basic human rights of life to health, happiness, and well-being.



OI education seminar and Q&A session led by Prof. Aman Pulungan, Dr. Dana Prihadi, Dr. Tiffany Shabrina, and Dr. Timothy Supit.



Sharing session led by parents of children living with OI.

CLAN are incredibly honoured to have worked with FOSTEO and YKAG in preparation of this event. Téa La, an intern working with CLAN and a New Colombo Plan (NCP) Scholar from the <u>Department of Foreign Affairs and Trade</u> (DFAT), was on the ground in Indonesia in the weeks leading up to the event, helping with the logistics. Leading up to the event, Téa was mentored by Jo Ragen to create the OI Child-friendly Rights Flyer, and collaborated with local professionals to create an OI education booklet. At the WBD event, Téa communicated with families and learned about some of their daily challenges. She found that this has further motivated her to continue the amazing efforts with CLAN. Sincerest gratitude to Jo Ragen, Craig Munns, Peter Simm, Dr. Jin-Ho, Kate Armstrong, Catherine Cole, and Prof. Aman Pulungan for supporting Téa in her journey with the OI community so far.



Téa (CLAN's Community Development Officer and DFAT's NCP Scholar), Ms. Yuan (President of FOSTEO), and Prof. Aman Pulungan.



Organisers from CLAN and YKAG with local health professionals.

The success of Wishbone Day 2023 in Indonesia was due to the combined efforts of the FOSTEO community, CLAN, YKAG, the Indonesian Pediatric Society, the team at Pondok Indah Hospital, Prof. Aman Pulungan, Dr. Dana Prihadi, Dr. Tiffanny Shabrina, Dr. Timothy Supit and all those who attended the event. The celebration came to fruition with the support and participation of everyone. Thank you!

This article by Téa La highlights the true passion of communities, professionals and partners seen at FOSTEO's Wishbone Day 2023 celebration, and the importance of collaborative efforts so that we #LeaveNoChildBehind.

## What are the Rights of the Child Living with Osteogenesis Imperfecta (OI)?

All children around the world have equal rights. These rights are declared by the United Nations Convention on the Rights of the Child (UNCRC) 1989. The international community has obligations to ensure no child is deprived of his or her rights, including access to health care services.

The United Nations declares all children must be fully prepared to live an individual life in society and brought up in the spirit of happiness, love, understanding, peace, dignity, tolerance, freedom, equality, and solidarity.

The World Health Organisation states all children, including those living with OI, have the right to "the highest attainable standard of health" and wellbeing without discrimination. This right includes access to facilities for the treatment of illness and rehabilitation.

Children, young people and their families living with OI and other chronic health conditions ask for help with five key action areas (CLAN's Five Pillars). UNCRC recognises these needs as the rights of all children.



An opportunity to live a healthy and happy life with Osteogenesis Imperfecta

