



2025 FOP Australia Conference

Provisional Program

**22nd -24th August, Holiday Inn Express Southbank,
Melbourne Australia**

We are delighted to invite Australians and New Zealanders with Fibrodysplasia Ossificans Progressiva, their families and supporters to this meeting. The program includes presentations, interactive sessions, and private family:clinician meetings, all aimed at providing knowledge, tools, and resources to help manage living with FOP.

The option for online attendance is currently being explored, and details will be confirmed once we have estimated numbers for online attendance from registration forms.

We will also be welcoming clinicians and researchers interested in learning more about FOP to attend the program. Information about additional concurrent sessions specifically for clinicians will be finalised in coming weeks.

Friday 22nd August

Start	End	Activity
11:00am	5:30pm	Family Welcome Room – Sandridge Room <i>Welcoming space available to register for the conference, meet attendees, interact with displays and resources, contribute questions for speakers, and enjoy refreshments.</i> Family Clinician Meetings (optional) - Walker Room <i>Private sessions (approximately 45 minutes duration each) offered to local families to meet with clinicians and discuss their care needs and treatment experiences thus far. We hope these will be opportunities for mutual learning sharing of experience and knowledge in a confidential setting. These sessions are optional and will be scheduled directly with each family who chooses this option on the registration form.</i> <i>Please note that this will not be a treatment consultation, but discussion notes can be provided for each family if they wish to discuss any points raised with their treating team.</i>
6:00pm	8:30pm	Meet and Greet Buffet <i>Informal dinner for conference attendees available during these times</i>

The information was updated on 9th May – there will be further updates as details are confirmed.
Suggestions and input are still welcome via info@fopaustalia.org.



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Saturday 23rd August

Start	End	Activity
7:30am	8:30am	Breakfast
8:45am	9:00am	Welcome: Day 1 of Presentations
9:00am	9:45am	Keynote presentation: <i>The Global FOP Research Landscape: What do we know, and what we have to learn</i> Dr Ed Hsiao – University of California San Francisco
9:45am	10:30am	Keynote presentation: <i>FOP Clinical Trials</i> Prof Rory Clifton-Bligh – Royal North Shore Hospital
10:30am	11:00am	Morning tea
11:00am	12:00pm	Virtual keynote presentation: <i>Lung health in FOP (including question time)</i> Prof Fred Kaplan – University of Pennsylvania Prof Robert Pignolo – Mayo Clinic College of Medicine
12:00pm	12:30pm	Panel Q+A session: <i>Trials and Treatments: Questions from this morning</i> Dr Hsiao, Prof Clifton-Bligh, Prof Kaplan, Prof Pignolo and community representatives
12:30pm	1:30pm	Lunch
1:30pm	2:00pm	Keynote presentation: <i>International Clinical Council on FOP: Guidelines for Management</i> Speaker TBC
2:00pm	2:30pm	Topic discussion: <i>What to expect when you're in enrolling in a clinical trial</i> Jean Doyle – Royal North Shore Hospital
2:30pm	3:00pm	Afternoon tea
3:00pm	3:30pm	Topic discussion: <i>Managing pain in FOP</i> Speaker TBC
3:30pm	4:00pm	Topic discussion: <i>Skin care in FOP</i> Speaker TBC
4:00pm	4:30pm	Topic discussion: <i>Dental care in FOP</i> Speaker TBC
4:30pm	5:15pm	Virtual keynote presentation: <i>Managing FOP flares / The role of palovarotene in FOP treatment</i> Prof Matt Brown – University of Oxford
5:15pm	6:00pm	Panel Q+A session: <i>All things FOP: What do you want to know?</i> Prof Brown, invited panelists and community representatives
6:00pm	6:10pm	Close of day 1 of presentations
7:00pm	10:30pm	Conference dinner

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Sunday 24th August

Start	End	Activity
7:30am	8:30am	Breakfast
8:45am	9:00am	Welcome: Day 2 of Presentations
9:00am	9:45am	Resource update: IFOPA Ability Toolbox Speaker TBC
9:45am	10:30am	Topic discussion: Seeking psychosocial support Facilitator details TBC With a recorded message from Neale Daniher, 2025 Australian of the Year
10:30am	11:00am	Morning tea
11:00am	11:15am	Resource update: Grant programs: IFOPA and FOP Australia Speaker TBC
11:15am	11:30am	Topic discussion: FOP Patient Registry Speaker TBC
11:30am	12:25pm	FOP Australia 2024/2025 Annual General Meeting
12:25pm	12:30pm	Close of conference
12:30pm	1:30pm	Lunch

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