



Ciliopathy Patient Meeting

September 09/10, University College Dublin

MONDAY SEPTEMBER 09

LOCATION: UCD CLUB (located in the same building complex as O'Reilly conference center)

From 10:00: **Registration**

Location: UCD Club entrance foyer

11:30 – 12:30 **Light lunch**

Location: UCD Club Restaurant (1st floor)

12:30: **Opening of Patient Day meeting**

Location: UCD Club Cedar/Cypress suite (1st floor)

Chair: Helen May-Simera

- Welcome address
- Introduction to panelists: Chris O'Callaghan, Jane Farrar, Fiona Copeland, Mieke Van Haelst, Rachel Giles, Mark de Leeuw, Phil Beales, John Sayer

13:15: **World Café – with Panelist members**

Location: UCD Club Cedar/Cypress & Beech/Birch suites (1st floor)

Chair: Helen May-Simera

- 3 x 20 min rotations (4 groups in Beech/Birch; 2 groups in Cedar/Cypress). Questions listed in program.

14:30: **Coffee Break**

Location: UCD Club 1st floor mezzanine

15:00: **Q and A with Panelists: Round 1**

Location: UCD Club Cedar/Cypress suite (1st floor)

Chair: Ruxandra Bachmann

Panelists: Chris O'Callaghan, Jane Farrar, Fiona Copeland, Mieke Van Haelst

Location: UCD Club Beech/Birch suite (1st floor)

Chair: Barbara Tanos

Panelists: Rachel Giles, Mark de Leeuw, Phil Beales, John Sayer

15:45: **Q and A with Panelists: Round 2**

Location: UCD Club Cedar/Cypress suite (1st floor)

Chair: Barbara Tanos

Panelists: Rachel Giles, Mark de Leeuw, Phil Beales, John Sayer

Location: UCD Club Beech/Birch suite (1st floor)

Chair: Ruxandra Bachmann

Panelists: Chris O'Callaghan, Jane Farrar, Fiona Copeland, Mieke Van Haelst

16:30: **Coffee Break**

UCD Club 1st floor mezzanine

17:00: **Explaining clinical trials & perspective on translational Research**

Location: UCD Club Cedar/Cypress suite (1st floor)

Chair: Bendert de Graaf

- 17:00: Mark-de Leeuw *Rhythm*
- 17:45 John Sayer *CILIAREN*
- 18:10 Phil Beales *Axovia*

18:30: **Networking Reception**

Location: O'Reilly conference center conservatory

19:30: **Drop-in information session for young adults**

Location: UCD Club Beech/Birch suite (1st floor)

TUESDAY SEPTEMBER 10

9:30-10:45: **World Café debrief**

Location: UCD Club Cedar/Cypress suite (1st floor)

Chair: Bendert de Graaf

11:00-11:10 **CILIA2024 opening**

Location: O'Reilly conference center auditorium

11:10-13:00 **CILIA2024 Session 1: Cilia Therapeutics**

Location: O'Reilly Conference center auditorium

13:00-14:00 **Lunch**

Location: O'Reilly conference center conservatory

14:00-15:30 **CILIA2024 Session 2: Ciliopathy Mechanisms**

Location: O'Reilly Conference center auditorium

15:30-17:30 **CILIA2024 Poster session A (including lay posters)**

Location: O'Reilly Conference center poster hall

17:30-19:15 **Patient-Scientist Exchange**

Location: O'Reilly conference center auditorium

Chair: Helen May-Simera

- 17:30: Introduction of Patient Organisations
- 17:50: Personal Perspective 1

- 18:05: Global Network Databases
- 18:15: Industry Perspective
- 18:25: Scientists Perspective
- 18:35: Personal Perspective 2
- 18:50: Personal Perspective 3
- 19:05: Tess Harris Memorial Tribute

19:15-21:30 **CILIA2024 Welcome Reception**

Location: O'Reilly conference center conservatory