



TOWARDS AN UNDIAGNOSED DISEASES PROGRAM (UDP) IN NSW

9:00 am - 4:00 pm 27 June 2016, John Shine Room

Level 6 The Kinghorn Cancer Centre, 370 Victoria St Darlinghurst

OBJECTIVES

- Learn from the experience of Western Australia in their Undiagnosed Diseases Program (UDP)
- Discuss practical steps towards a UDP node or nodes in NSW
- Determine capabilities available to a UDP node
- Draft processes and workflows for considering cases for a UDP node
- Identify individuals who could be involved in the UDP node's workflows

9:00 am - 9:30 am	Registration
9:30 am - 10:00 am	Welcome and introduction
10:00 am - 10:15 am	Policy, the transformative step for people living with Rare and Undiagnosed Diseases Professor Hugh Dawkins (Office of Population Health Genomics – WA Department of Health)
10:15 am - 10:45 am	An overview of the UDP and the WA experience Clinical Associate Professor Gareth Baynam (Genetic Services of WA)
10:45 am - 11:00am	Steps towards a UDP node in NSW Professor Andreas Zankl (Sydney Children's Hospital Network, Westmead)
11:00 am - 11:30 am	Morning tea
11:30 am - 12:00 pm	Patient Archive - an electronic coordination platform for the UDP Dr Tudor Groza (Kinghorn Centre for Clinical Genomics)
12:00 pm - 12:30 pm	Using WGS to solve undiagnosed diseases Associate Professor Marcel Dinger (Kinghorn Centre for Clinical Genomics)
12:30 pm - 12:45 pm	Health services perspectives and potential benefits to patients Associate Professor Yvonne Zurynski (Sydney Children's Hospital Network, Westmead)
12:45 pm - 1:00 pm	Closing remarks
1:00 pm - 2:00 pm	Lunch
2:00 pm - 4:00 pm	Workshop to discuss establishment of a UDP node
4:00 pm - 5:00 pm	Close and reception

Hosted by:

KINGHORN
CENTRE
FOR CLINICAL
GENOMICS

