**Rare Disease Day 28 February 2018**

**WA Insights in Lights - Symposium Schedule**

|  |  |
| --- | --- |
| 9.30 am – 9.45 am | Registrations |
| 9.45 am – 10.05 am | Welcome to Country (TBA) |
|  | The Hon Malcolm McCusker AC CVO QC – Opening Remarks (confirmed)Prof Peter Klinken AC – Welcome to the Symposium (TBC) |
|  **Panel Discussions – Patient and Researcher Collaboration** |
| 10.05 am – 10.40 am | Rachel Callander |
|  (35 mins) | *The Impact of Effective Communication Between Parent and Professional* |
| 10.40 am – 11.00 am | **MORNING TEA and NETWORKING (20 minutes)** |
| 11.00 am – 12.00 am | Telethon Kids |
|  (45 mins) | *Genetic and Rare Disease Research speakers*  |
| 12.00 am – 12.15 am | SUMMARY – Facilitator (Rachel Callendar)  |
|  (15 mins) |
| 12.15 pm – 1.15 pm | **LUNCH AND NETWORKING (60 minutes)** |
|  **Presentations (includes Q&A)** |
| 1.15 pm – 1.45 pm | Professor Nigel Laing |
|  (30 mins) | *Patient Centred Research* |
| 1.45 pm – 2.30 pm | Dr Gareth Baynam |
|  (45 mins) | *Diagknowsis – The Power of the Answer*  |
| 2.30 pm – 3.00 pm | **AFTERNOON TEA (30 minutes)** |
| 3.00 pm – 3.30 pm | Nicole Millis  |
|  (30 mins) | *The Call for a National Rare Disease Framework* |
| 3.30 pm – 4.00 pm | Klair Bayley  |
| (30 mins) | *The Muscular Dystrophy Experience* |
| 4.05 pm – 4.20 pm | SUMMARY – Facilitator (Rachel Callendar) |
|  (15 mins) |  |
|  **Facilitated Workshop – Future of Rare Diseases – Vision for 2020**  |
| 4.20 pm – 5.05 pm | Professor Hugh Dawkins – (OPHG) Policy and practice in WA (Confirmed) |
|  (45 mins) | Professor John Challis – WAHTN and research in rare disease (Confirmed) |
|  | Amanda Samanek – Genetic and Rare Disease Network (GaRDN) (Confirmed) |
|  | Melissa Devlin - Genetic and Rare Disease Network – Board Chair and living with a rare condition |
|  **Symposium Closure and Rare Disease Day Awards 2018** |
| 5.05 pm – 5.20 pm | Honourable Roger Cook MLA, Minister for Health, Western Australia (To be confirmed) |
| 5.30 pm – 7.30 pm | Gathering on the Terrace for canapes and inaugural Rare Disease Day Awards 2018Perth Council Building Feature Lighting to mark Rare Disease Day in Western Australia. |