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**4th Annual iCAN Research & Advocacy Summit**

**Agenda**

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| **Sunday July 8****Southhall Pollock Halls****Welcome and Orientations** |
| **15:00 - 16:00** | **Registration and Welcome Desk Open** |  |
| **15:00 - 16:00**  | **Pod Facilitators Meet/Greet** |  |
| **16:00 - 17:00**  | **Leadership Breakout** |  |
| **16:00 - 17:00**  | **Youth Pod Leader Meet/Greet** |  |
| **17:00 - 18:30**  | **Speed Presentations** |  |
| **18:30 - 17:00**  | **Welcome BBQ** |  |

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| **Plenary** **09:00 - 09:05** | **Summit Welcome: Charlie Thompson ICAN Chair** |  |
| **09:05 - 09:30**  | **Opening Address: Maureen Watt Member Scottish Parliament- Minister for Mental Health** |  |
| **09:30 - 10:00**  | **How Drug Development Changed Outcomes for Respiratory Disease: Professor Steve Cunningham** |  |
| **10:00 - 11:00** | **Clinical Trial Design: Dr Alun Hughes**  |  |
| **11:00 - 11:30** | **Coffee/Tea Break** |  |
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|  | **Youth Workshops** |  |
| **11:30 - 12:30** | **Designing Patient Information Sheets (Jennifer Preston), Formulations (Prof Matthew Peake, Dr Louise Bracken, Jennifer Duncan, Emma McDonough ), and Clinical Trial Design (Dr Alun Hughes)** | **Salisbury, Pentland West,** **and Holyrood** |
| **12:30 - 13:30** | **Catered Lunch** | **Restaurant Self Service** |
| **13:30 – 15.30** | **Swap workshops x2**  | **Salisbury, Pentland West,** **and Holyrood** |
| **15:30 - 17:00** | **Drug Discovery Challenge: Write Your Protocols!** | **Salisbury, Pentland West,** **and Holyrood** |
| **17:00 - Evening** | **Free Time** |  |

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|  | **Parent and Facilitator Workshops** |  |
| **11:30 - 12:30** | **Future Leadership Directions: Leanne West, Christine Woods, and Laura McMaster** | **Pentland East** |
| **12:30 - 13:30** | **Catered Lunch** | **Restaurant Self Service** |
| **13:30 - 15:30** | **Social Media: Using Twitter to Promote iCAN, your chapter, and your projects. Keeping vulnerable members safe: Simon Cree and Simon Stones** | **Pentland East** |
| **15:30 - 17:00** | **Business Meeting: Parents and Facilitators** | **Pentland East** |

**Tuesday July 10**

**Southhall Pollock Halls**

**Educational and Rare Disease Day**

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| **Plenary** |  |  |
| **09:30 - 10:00** | **What is a rare disease, and how do we use international registries/networks to improve healthcare for children with rare diseases? Dr Martina Rodie** | **Southhall** |
| **10:00 - 10:45** | **Ethics of Doing Research with Children: Dr Bob Phillips** | **Southhall** |
| **10:45 - 11:00** | **Coffee/Tea Break** |  |
| **11:00 - 11:30** | **Why Fit in When You Were Born to Stand Out? Benjamin James and Simon Stones** | **Southhall** |
| **11:30 – 11.45****11.45 - 12.00** | **When medicines change lives- My experience with JIA and transitioning to University. Anna Sherriffs** **A Parent’s Perspective: Frankie’s Journey with Dravet’s: Stacey Hutchison** | **Southhall****Southhall** |
| **12:00 - 12:15****12.15 - 12.45** | **Advocating for Children with Type 1 Diabetes in the US: Reece Ohmer and Olivia Ohmer** **Panel QA**  | **Southhall** |
| **12:45 - 13:45** | **Catered Lunch** | **Kirkland** |

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|  | **Youth Workshops** |  |
| **13:45 - 14:30** | 1. **Drug Discovery Challenge: Dr Alun Hughes**
2. **Can you imagine a word without antibiotics?**

**Dr Nicholas Brown, Dr Enas Newire**1. **Ethics: Dr Bob Phillips**
 | **VIP/Foyer****Southhall****Kirkland** |
| **VIP14:30 - 16:30** | **Swap Workshops x2** | **As above** |
| **16:30 - 17:30** | **Designing a Project from Concept to Delivery for 16 plus YP: Dr. Sharon Smith** | **Southhall** |

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|  | **Parent and Facilitators Workshops** |  |
| **13:45 - 14:30** | **Digital Patient Records: Christine Woods** | **Absorb** |
| **14:30 - 16:30** | **How to Develop, Run, and Manage an iCAN Chapter: Begonya Escalera, Segolene Gaillard** | **Absorb** |
| **16:30 - 17:30** | **The Role of a Research Nurse: the patient’s advocate, Susan MacFarlane and Liz Waxman** | **Absorb** |
| **19:00** | **Meal Out and Ghost/Horrible Histories Tour of Old Edinburgh** |  |
| **Wednesday July 11****Southhall Pollock Halls** **Improving Health and Quality of Life** |
| **Plenary****09:30 - 10:15** | **Improving Health and Quality of Life with Singing: Professor Graeme Wilson** | **Southhall** |
| **10:15 - 10:35** | **The individual's journey within the music therapy process "See me, hear me, listen to me,” Brian Smith** | **Southhall** |
| **10:35 - 11:05** | **Determinants of a Child's Health: Vivian Tsang** | **Southhall** |
| **11:05 - 11:20** | **Coffee/Tea Break** |  |
| **11:20 - 11:50**  | **Genetic Testing - to know or not to know? Jessica Lorimer, Saskia Oosterveld, Oliver Tailby**  | **Southhall** |
| **11.50 - 12:45** | **Youth Perspectives on Living with a Rare Condition** **Living and Advocating with an Invisible Illness, Sophie Ainsworth****When You Wake Up after a Nightmare, Marta Botanch** **An Uncommon Life with an Uncommon Condition, Hampton Woods** | **Southhall** |
| **12:45 - 14:00** | **Working Lunch: Pods** |  |
| **14:00 - Evening** | **Free time – Explore Edinburgh**  |  |

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| **Thursday 12 July****Southhall Pollock Halls** **iCAN Young Informers** |
| **Plenary** **09:00 - 09:30** | **#datasaveslives: Steph Wright** |  |
| **09:30 - 10:00** | **Learning what the risks from new medicines could be: how patients can help: Dr Dan Hawcutt** |  |
| **10:00 - 10:30** | **Who does what? Industry, Contract research organisations and the regulator? Claudio Fracasso, Cindy Jackson, Dr Angeliki Siapkara** |  |
| **10:30 - 10:45** | **A Career in Drug Development? Dr Sue Tansy**  |  |
| **10:45 - 11:00** | **Coffee/Tea Break** |  |
| **11:00 - 13:00** | **Workshops and Seminars in groups see table below** |  |
| **1:00-2:00** | **Catered Lunch** |  |
| **14:00 - 17:30** | **Workshops Continued** |  |
| **17:30 - evening** | **Fish and Chips and Mini-Highland Games**  |  |

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| **Friday July 13****Dynamic Earth** **Technology The Future of Medicine**  |
| **08:30** | **Leave Accommodation, Venue Change** |  |
| **09:30 - 11.30****11.30 - 12.00** | **Drug Discovery Challenge - Presentations****Technology for Sharing Patient Generated Data: friend or foe? Elin Haf Davies** |  |
| **12.00 - 12.30**  | **Technology and Devices for Children’s Health: Paul Dimitris** |  |
| **12:30 - 13:00** | **Catered Lunch** |  |
| **13:00 - 15:30** | **Technology Exhibition Sessions****Technology Innovation Transforming Child Health****Tookie****Pneumacare****Child Prosthetics, Limb Power and Open Bionics****Strathclyde University** |  |
| **15:30 - 17:00** | **Optional Tour Dynamic Earth** |  |

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**Thursday 12 Workshops**

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| **Colour Code** | **Group 1 CYP** | **Group 2 CYP** | **Facilitators, parents and supporters** |  |
| **Room** | **Southhall** | **Kirkland** | **Absorb**  | VIP |
| Time |   |   |   |   |
| 11.00-11.45 | Pfizer | El Lilly | PRA |   |
| 11.45-12.30 | PRA | Yellow Card Scheme | IQVIA |   |
| 12.30-13.00 | Premier  | Synteract | Pfizer |   |
| 13.00-14.00 | LUNCH |   |   |   |
| 14.00-14.30 | Synteract | Premier | Yellow Card Scheme |   |
| 14.30-15.15 | COMET (Univ Liv) | Pfizer |   |   |
| 15.15-16.00 | Yellow Card Scheme | AAP |   | Clinical Trial Challenge |
| 16.00-16.45 | El Lilly | PRA |   |   |
| 16.45-17.30 | Clinical Trial Challenge | COMET (Univ Liv) | TBC |   |