





Pioneering Our PKU Future

PKUGLOBE22

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| STEP 1: PICK YOUR NEAREST TIMEZONE | REGION | DAY 1 | DAY 2 | Day 3 | Day 4 | Day 5 | Day 6 |
|------------------------------------|------------------------------------|---|--|--|--|--|--|
| | Asia Pacific (Melbourne - AEDT) | Fri 9 th Dec 7am - 9.00am AEDT | Sat 10 th Dec 7am - 9.00am AEDT | Sun 11 th Dec 7am - 9.00am AEDT | Mon 12 th Dec 7am - 9.00am AEDT | Tue 13 th Dec 7am - 9.00am AEDT | Wed 14 th Dec 7am - 9.00am AEDT |

MAINSTAGE – 6 DAY PROGRAM

|  STEP 2: WATCH ON DEMAND OR PARTICIPATE REAL-TIME LIVE EACH DAY  TUNE IN LIVE (up to 2 hrs each day)  | THEMES | Phenylketonuria - Where it all began | Global PKU Gaps | Diagnosis & Access to care | Management & Monitoring | Adults & Teens | Global PKU Emergencies |
|---|--|--|---|---|--|--|--|
| | DAILY ON DEMAND...  | <ul style="list-style-type: none"> The Discovery History, Heroes of PKU The Legacy of Prof. Horst Bickel The Legacy of Robert Guthrie The forgotten Children | <ul style="list-style-type: none"> Identifying the GAPS in care around the globe The Empowering Role of Advocacy The Importance of Rare Disease Patient Registries | <ul style="list-style-type: none"> The future for International Newborn screening Newborn Screening in Guatemala The UN resolution on Rare Disease for PKU | <ul style="list-style-type: none"> Home Phe Monitoring Tue into the Low Phe Life Cartoon Channel | <ul style="list-style-type: none"> PKU Return to Care (Diet & Treatment) Co-Morbidities relating to PKU Maternal PKU Adults & Teens Panel (NPKUA) LNAA's (Large Neutral Amino Acid Therapies) Adults & Teens Panel | <ul style="list-style-type: none"> Ukraine/Russian Conflict and the impact on management of PKU for all impacted. |
| PATIENT PANEL: The pioneers of early diagnosis. | PATIENT PANEL: The pioneers of early diagnosis. | GAP PANEL: WHY GAP? Supporting global PKU priorities. | PATIENT PANEL: GAPS in diagnosis & access to care. | EXPERT PANEL: PKU Clinical Practice Guidelines PKU guidelines across the globe | PATIENT PANEL: International Traveller Tips. | PATIENT PANEL: The issue of Health Migration. | |
| PKU CHATS & Q&A: Meet up with other PKU Pioneers, Influencers and change makers from around the globe. Join a Q&A with Synlogic. | PKU CHATS & Q&A: Meet up with other PKU Pioneers, Influencers and change makers from around the globe. Join a Q&A with Synlogic. | PRESENTATION & Q&A: Understanding PKU: Looking beyond the Ivory Tower Metabolism Clinic | PKU CHATS & Q&A: Meet up with other PKU Patients around the globe and chat with On Demand Presenters and also Synlogic. | PKU CARTOON NETWORK: Meet the filmmaker – Win a self-animation PKUGLOBE PEN PAL CLUB: Meet up with other PKU Kids around the globe & find a PKUGlobe Pen Pal. | Wellbeing - Thriving with PKU A wellness session for PKU Adults. | PKU ADVOCACY WORKSHOP: For patient advocates & future leaders. (limited spaces avail – pre registration essential) | |
| FACILITATED Q&A: Filling the gap on patient outcomes and PKU disease | FACILITATED Q&A: Filling the gap on patient outcomes and PKU disease | | | | PKU CHATS: Meet up with other PKU Patients around the globe and chat with On Demand Presenters | | |

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| | | | | | 🕒 PKU CHATS & Q&A: Meet up with other PKU Patients around the globe and chat with On Demand Presenters from Home Phe Monitor companies | | |
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SHOWCASE – PROGRAM

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| STEP 3: VIEW SHOWCASE CONTENT ANYTIME  | PKU 2021 & 2022 – ENCORE The best from 2021 & 2022 PKU conference around the globe | | | | PKU SCIENTIFIC HALL | |
| | ESPKU ENCORE | MDDA ENCORE | NPKUA ENCORE | PKUGLOBE21 ENCORE | Latest PKU Scientific Research & Sponsored Presentations. Synlogic: Transforming Medicine Through Synthetic Biology Homology: Gene Editing for PKU | |

HOW TO GET INVOLVED IN PKUGLOBE22...

- Register to attend and tune in daily or anytime during the 6 day program
- Apply for participate in our Global PKU Advocacy Workshop (limited spaces)
- Join PKUGlobe PEN PAL club and upload your child’s profile to meet other PKU PEN PALS around the globe
- Share our event with other PKU Friends and through social media to broaden our PKU audience each day
 - Contact us if you have other topics or content you would like to see added to this years program

www.pkuglobe.org



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