





# Pioneering Our PKU Future

PKUGLOBE22


STEP 1: PICK YOUR NEAREST TIMEZONE	REGION	DAY 1	DAY 2	Day 3	Day 4	Day 5	Day 6
	Europe (London GMT)	LIVE ● Thurs 8 <sup>th</sup> Dec 8pm – 10.00pm GMT	Fri 9 <sup>th</sup> Dec 8pm – 10.00pm GMT	Sat 10 <sup>th</sup> Dec 8pm – 10.00pm GMT	Sun 11 <sup>th</sup> Dec 8pm – 10.00pm GMT	Mon 12 <sup>th</sup> Dec 8pm – 10.00pm GMT	Tue 13 <sup>th</sup> Dec 8pm – 10.00pm GMT

## MAINSTAGE – 6 DAY PROGRAM

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

					🕒 <b>PKU CHATS &amp; Q&amp;A:</b> 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**

<b>STEP 3: VIEW SHOWCASE CONTENT ANYTIME</b> 	<b>PKU 2021 &amp; 2022 – ENCORE</b> The best from 2021 & 2022 PKU conference around the globe				<b>PKU SCIENTIFIC HALL</b>		
	<b>ESPKU ENCORE</b>	<b>MDDA ENCORE</b>	<b>NPKUA ENCORE</b>	<b>PKUGLOBE21 ENCORE</b>	Latest PKU Scientific Research & Sponsored Presentations. <b>Synlogic:</b> Transforming Medicine Through Synthetic Biology <b>Homology:</b> 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](http://www.pkuglobe.org)



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