





Pioneering Our PKU Future

PKUGLOBE22

🕒 2 hours concurrent livestream each day EST


STEP 1: PICK YOUR NEAREST TIMEZONE	REGION	DAY 1	DAY 2	Day 3	Day 4	Day 5	Day 6
	America (Atlanta - EST)	Thurs 8 th Dec 3pm – 5.00pm EST	Fri 9 th Dec 3pm – 5.00pm EST	Sat 10 th Dec 3pm – 5.00pm EST	Sun 11 th Dec 3pm – 5.00pm EST	Mon 12 th Dec 3pm – 5.00pm EST	Tue 13 th Dec 3pm – 5.00pm EST

MAINSTAGE – 6 DAY PROGRAM

	THEMES	Phenylketonuria - Where it all began	Global PKU Gaps	Diagnosis & Access to care	Management & Monitoring	Adults & Teens	Global PKU Emergencies
 STEP 2: WATCH ON DEMAND OR PARTICIPATE REAL-TIME LIVE EACH DAY  TUNE IN LIVE ● (up to 2 hrs each day) 	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.
	<ul style="list-style-type: none"> 🕒 PATIENT PANEL: The pioneers of early diagnosis. 🕒 PKU CHATS & Q&A: Meet up with other PKU Pioneers, Influencers and change makers from around the globe. Join a Q&A with Synlogic. 	<ul style="list-style-type: none"> 🕒 PATIENT PANEL: WHY GAP? Supporting global PKU priorities. 🕒 PRESENTATION & Q&A: Understanding PKU: Looking beyond the Ivory Tower Metabolism Clinic 🕒 FACILITATED Q&A: Filling the gap on patient outcomes and PKU disease 	<ul style="list-style-type: none"> 🕒 PATIENT PANEL: GAPS in diagnosis & access to care. 🕒 PKU CHATS & Q&A: Meet up with other PKU Patients around the globe and chat with On Demand Presenters and also Synlogic. 	<ul style="list-style-type: none"> 🕒 EXPERT PANEL: PKU Clinical Practice Guidelines PKU guidelines across the globe 🕒 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. 	<ul style="list-style-type: none"> 🕒 PATIENT PANEL: International Traveller Tips. 🕒 Wellbeing - Thriving with PKU A wellness session for PKU Adults. 🕒 PKU CHATS: Meet up with other PKU Patients around the globe and chat with On Demand Presenters 	<ul style="list-style-type: none"> 🕒 PATIENT PANEL: The issue of Health Migration. 🕒 PKU ADVOCACY WORKSHOP: For patient advocates & future leaders. (limited spaces avail – pre registration essential) 	

					🕒 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

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

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