

Global PKU Patient Conference - Multi-Timezone Program - Thursday December 8 to Wednesday December 14, 2022

VIRTUAL SHOWCASE & RESEARCH HALL - OPEN ENTIRE EVENT

SHOWCASE OPEN 24/7 WITH CONTENT ON DEMAND

GLOBAL PATIENT GROUP SHOWCASE & EVENT CONTENT ENCORE, SOCIAL HUB & SCAVENGER
 ENCORE PRESENTATIONS FROM ESPKU, MDDA & NPKUA 2022 CONFERENCES
 ENCORE PRESENTATIONS FROM GLOBAL PKU 2021 CONFERENCE
Latest PKU Scientific Research & Sponsored Presentations
 Synlogic: Transforming Medicine Through Synthetic Biology
 Homology: Gene Editing for PKU

LIVE session

Webcam session - webcam access requested (you can turn off) Live session - NO webcam access requested (audience Q&A Box only)

AMERICA EUROPE AUSTRALIA

EST GMT AEDT 8th Dec DAY 1: THEME Phenylketonuria - Where it all began

THUR 8 THUR 8 THUR 8 DURATION ON DEMAND CONTENT (Released 12 hours prior to LIVE sessions each day and remain available until end of conference)

12 Hours prior to LIVE SESSIONS

until end of day 6

The History of PKU	John Adams, Co-Founding Trustee and Board Chair, GAP
The Discovery of PKU & The Heroes of PKU	Dr. Harvey Levy - Heroes of PKU - Asbjørn Følling Lecture 2012
The Legacy of Prof. Horst Bickel & The discovery of the PKU Diet	Proudly created and presented by DIG PKU
The Forgotten Children	Proudly created and presented by DIG PKU
Introducing the Newborn Screening Test by Dr. Robert Guthrie	Dr. Robert Guthrie (from 1970)

THUR 8 THUR 8 FRI 9 DURATION LIVE SESSIONS (2 Hours of Live content)

3.00pm	8.00pm	7.00am	1 Hour	PATIENT PANEL: THE PIONEERS OF EARLY DIAGNOSIS	PKU Pioneers: Debbie Colyer OAM Charles Black Duncan Noble-Nesbitt John Adams, CANPKU (FACIL)
4.00pm	9.00pm	8.00am	1 Hour	PKU LIVE CHATS	Join a chat room and meet others
4.30pm	9.30pm	8.30am	30 mins	LIVE Q&A Drop In's	Drop In and have a chat or ask a question of our On Demand presenters: Feat. Synlogic - Transforming Medicine Through Synthetic Biology

THUR 8 THUR 8 FRI 9 DURATION INTERACTIVE ACTIVITIES

3.00pm	8.00pm	7.00am	2 Hours	SOCIAL HUB, CHAT ROOMS, LIVE Q&A's AND SCAVENGER HUNT ACTIVITIES	Some On Demand Presenters available in Chat Rooms for Live Q&A
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* Note: AEDT is one day ahead for LIVE sessions given time difference

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EST GMT AEDT DURATION DAY 2: THEME Global PKU Gaps

FRI 9 FRI 9 FRI 9 DURATION ON DEMAND CONTENT (Released 12 hours prior to LIVE sessions each day and remain available until end of conference)

12 Hours prior to LIVE SESSIONS

until end of day 6

Identifying the GAPS in PKU care around the globe	Various GAP Member association trustees present "PKU in my country"
The Importance of Rare Disease Patient Registries	Pamela Gavin, Executive Vice President of the U.S. National Organization for Rare Disorders + Live facilitated Q&A
PKU and the Empowering Role of Advocacy	Bernadette Gilroy, PKU Association of Ireland

FRI 9 FRI 9 SAT 10 DURATION LIVE SESSIONS (2 Hours of Live content)

3.00pm	8.00pm	7.00am	1 Hour	GAP PANEL: WHY GAP? Supporting global PKU priorities.	GAP Trustees: John Adams, CANPKU Louise Healy, MDDA Cristian Baigorria, PKU Canada José de Jesús Muñoz Navarro, PKU Mexico Tobias Hagedorn, DIGPKU (FACIL)
4.00pm	9.00pm	8.00am	30 mins	PRESENTATION & FACILITATED Q&A: Understanding PKU - Looking beyond the Ivory Towers Metabolism Clinic	Dr. Mark Korson, MD, VMP Genetic John Adams, Co-Founding Trustee and Board Chair, GAP (FACIL)
4.30pm	9.30pm	8.30am	30 mins	FACILITATED Q&A: Filling the gap on patient outcomes and PKU disease	Pamela Gavin, Executive Vice President of the U.S. National Organization for Rare Disorders John Adams, Co-Founding Trustee and Board Chair, GAP (FACIL)

FRI 9 FRI 9 SAT 10 DURATION INTERACTIVE ACTIVITIES

3.00pm	8.00pm	7.00am	2 Hours	SOCIAL HUB, CHAT ROOMS, LIVE Q&A's AND SCAVENGER HUNT ACTIVITIES	Some On Demand Presenters available in Chat Rooms for Live Q&A
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AMERICA		EUROPE		AUSTRALIA				DAY 3: Diagnosis & Access to care	
EST	GMT	AEDT	DURATION						
SAT 10	SAT 10	SAT 10	DURATION	ON DEMAND CONTENT (Released 12 hours prior to LIVE sessions each day and remain available until end of conference)					
				Newborn Screening in Guatemala		Paula Luna Ovalles			
SAT 10	SAT 10	SUN 11	DURATION	LIVE SESSIONS (2 Hours of Live content)					
3.00pm	8.00pm	7.00am	1 Hour	🕒 PATIENT PANEL: GAPS in diagnosis & access to care priorities.		🗣️ Global Patient Group Representatives: Lal Atakay, PKU Turkey Dr. Paula Vargas, PKU Brasil Cristian Baigorria, PKU Canada José de Jesús Muñoz Navarro, PKU Mexico Tobias Hagedorn, PKUDIG (FACIL)			
4.00pm	9.00pm	8.00am	30 mins	🕒 PRESENTATION & FACILITATED Q&A: The Future for International Newborn screening		🗣️ Dr. James Bonham, President of the International Society for NeoNatal Screening			
4.30pm	9.30pm	8.30am	30 mins	🕒 PRESENTATION & FACILITATED Q&A: The UN resolution on Rare Disease for PKU		🗣️ Durhane Wong-Rieger, President & CEO at Canadian Organization for Rare Disorders			
4.30pm	9.30pm	8.30am	30 mins	🕒 LIVE Q&A Drop In's		🗣️ Drop In and have a chat or ask a question of our On Demand presenters: Synlogic - Transforming Medicine Through Synthetic Biology			
SAT 10	SAT 10	SUN 11	DURATION	INTERACTIVE ACTIVITIES					
3.00pm	8.00pm	7.00am	2 Hours	SOCIAL HUB, CHAT ROOMS, LIVE Q&A's AND SCAVENGER HUNT ACTIVITIES		Some On Demand Presenters available in Chat Rooms for Live Q&A			

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AMERICA		EUROPE		AUSTRALIA				DAY 4: Management & Monitoring	
EST	GMT	AEDT	DURATION						
SUN 11	SUN 11	SUN 11	DURATION	ON DEMAND CONTENT (Released 12 hours prior to LIVE sessions each day and remain available until end of conference)					
12 Hours prior to LIVE SESSIONS			until end of day 6	Home Phe Monitoring		Various companies presenting their project status on Home Phe monitoring + Avail in Q&A chat room LIVE			
				Low Phe Life Cartoon Channel - Watch special screening of the Low-Phe Life cartoon episodes		Kurt Sensenbrenner, Documentary Director & Producer, The lowphe life + Avail in Q&A chat room LIVE			
SUN 11	SUN 11	MON 12	DURATION	LIVE SESSIONS (2 Hours of Live content)					
3.00pm	8.00pm	7.00am	1 Hour	🕒 EXPERT PANEL: PKU Clinical Practice Guidelines PKU guidelines across the globe		🗣️ Anita Inwood, Director, Queensland Lifespan Metabolic Medicine Service. Prof Dr. Anita MacDonald, Birmingham Children's Hospital NHS Foundation Trust Francjan van Spronsen, Head of the Division of Metabolic Diseases in the Beatrix Children's Hospital of the University Medical Center of Groningen Dr. Jerry Vockley, Director, Center for Rare Disease Therapy, UPMC Children's Hospital of Pittsburgh Louise Healy MDDA & co-			
4.00pm	9.00pm	8.00am	1 Hour	🕒 PKU CARTOON TIME: Meet the Low-Phe Life filmmaker and discuss your own animated story		🗣️ Kurt Sensenbrenner, The lowphe life (www.lowphelife.com)			
				🕒 PKUGLOBE PEN PAL CLUB: Meet up with other PKU Kids around the globe & find a PKUGlobe Pen Pal		🗣️ Meet & connect with PKU kids around the globe			
4.30pm	9.30pm	8.30am	30 mins	🕒 PKU LIVE CHATS		🗣️ Join a chat room and meet others			
4.30pm	9.30pm	8.30am	30 mins	🕒 LIVE Q&A Drop In's		🗣️ Drop In and have a chat or ask a question of our On Demand presenters: Feat. our Home Phe Monitoring			
SUN 11	SUN 11	MON 12	DURATION	INTERACTIVE ACTIVITIES					
3.00pm	8.00pm	7.00am	2 Hours	SOCIAL HUB, CHAT ROOMS, LIVE Q&A's AND SCAVENGER HUNT ACTIVITIES		Some On Demand Presenters available in Chat Rooms for Live Q&A			

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AMERICA EUROPE AUSTRALIA

EST	GMT	AEDT	DURATION	DAY 5: Adults & Teens	
MON 12	MON 12	MON 12	DURATION	ON DEMAND CONTENT (Released 12 hours prior to LIVE sessions each day and remain available until end of conference)	
12 Hours prior to LIVE SESSIONS				PKU Return to Care (Diet & Treatment)	Anne-Marie Desai, Clinical specialist Dietitian, Royal Melbourne Hospital
				Co-Morbidities in Adult PKU Patients - Organ involvement Kidney, Eye and Heart: becomes PKU a new phenotype?	From ESPKU Meeting Spain 2022 - Freidrich Trefz, Francios Maillot, Maria Gizewska, Reutlingen, Germany, Toulouse, France and Szczecin, Poland
				Maternal PKU	Prof Maria Gizewska (Dept. of Pediatrics, Endocrinology, Diabetology, Metabolic Diseases and Cardiology, NPKUA hosted PKU Adults & Teens panel
				Adults & Teens Panel (From NPKUA)	
MON 12	MON 12	TUE 13	DURATION	LIVE SESSIONS (2 Hours of Live content)	
3.00pm	8.00pm	7.00am	45 mins	🕒 PATIENT PANEL: International Traveller Tips	🕒 PKU Adults: International PKU Adult travellers; Yasmeen Golden, PKU Adult America Maria Depenweiller, PKU Adult Canada Bianca Albanese, PKU Adult Australia (FACIL)
3.45pm	8.45pm	7.45am	45 mins	🕒 Wellbeing - Thriving with PKU. A wellness session for PKU Adults	🕒 Louise Healy, MDDA Vice President and founding GAP trustee
4.30pm	9.30pm	8.30am	30 mins	🕒 Large Neutral Amino Acid Therapies and Phenylketonuria: A promising approach to treatment	🕒 Kirsten Ahring, Cand. Scient i Human Ernæring, Ph.d. Centre for PKU, Denmark
4.30pm	9.30pm	8.30am	30 mins	🕒 LIVE Q&A Drop In's	🕒 Drop In and have a chat or ask a question of our On Demand presenters: Feat. Maria Gizewska, Synlogic &
MON 12	MON 12	TUE	DURATION	INTERACTIVE ACTIVITIES	
3.00pm	8.00pm	7.00am	2 Hours	SOCIAL HUB, CHAT ROOMS, LIVE Q&A's AND SCAVENGER HUNT ACTIVITIES	Some On Demand Presenters available in Chat Rooms for Live Q&A

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AMERICA EUROPE AUSTRALIA

EST	GMT	AEDT	DURATION	DAY 6: Global PKU Emergencies	
TUE 13	TUE 13	TUE 13	DURATION	ON DEMAND CONTENT (Released 12 hours prior to LIVE sessions each day and remain available until end of conference)	
12 Hours prior to LIVE SESSIONS				The PKU Emergency in Ukraine and Eastern Europe - The power of patient group collaboration	Recorded sessions from ESPKU 2022 Patient Conference.
TUE 13	TUE 13	WED 14	DURATION	LIVE SESSIONS (2 Hours of Live content)	
3.00pm	8.00pm	7.00am	1 Hour	🕒 PATIENT PANEL: The issue of Health Migration	🕒 Ahmad Reshad Noori, PKU Afghanistan Albina, PKU Ukraine Dr. Paula Vargas, PKU Brasil Elena Balabanova, PKU Moscow Cristian Baigorria, PKU Canada Tobias Haedorn PKUDIG (FACIL)
4.00pm	9.00pm	8.00am	1 Hour	🕒 PKU ADVOCACY WORKSHOP: For patient advocates & future leaders (limited spaces avail)	🕒 GAP Patient Group Representatives & Trustees: Louise Healy, MDDA and Bernadette Gilroy PKU Ireland
TUE 13	TUE 13	WED 14	DURATION	INTERACTIVE ACTIVITIES	
3.00pm	8.00pm	7.00am	2 Hours	SOCIAL HUB, CHAT ROOMS, LIVE Q&A's AND SCAVENGER HUNT ACTIVITIES	Some On Demand Presenters available in Chat Rooms for Live Q&A

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EST	GMT	AEDT	DURATION	DAY 6: SPECIAL FEATURED NON ENGLISH SPEAKING PROGRAM	
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AMERICA	EUROPE	AUSTRALIA	EST	GMT	AEDT	DURATION	SPECIAL FEATURED - PORTUGUESE SPEAKING SESSIONS	
TUE 13	TUE 13	WED 14					LIVE SESSIONS (2 Hours of Live content)	
5.00pm	10.00pm	9.00am	2.55 Hrs	🕒 A Brazilian-Portuguese PKU Journey (In Portuguese)		Featuring brazilian and portuguese experts and patients for PKUers in Brazil-Portugal		
5.00pm	10.00pm	9.00am	1.35 Hrs	<ul style="list-style-type: none"> - Welcome - Brasil in a brief PKU context - Portugal: Brief PKU context - Role of differents protein substitutes - Importance of low protein foods for PKU - How is the diet treatment done in Brasil? - Discussion 		DRA. PAULA R. VARGAS (MD – PKU EXPERT BRAZIL) DR. JÚLIO CÉSAR ROCHA (PROFESSOR OF NUTRITION – PKU EXPERT PORTUGAL) CATARINA RODRIGUES - (DIETITIAN - PKU EXPERT PORTUGAL) ALEX PINTO - (DIETITIAN PKU EXPERT PORTUGAL) MARIA EFIGENIA QUEIROS LEITE (DIETITIAN – PKU EXPERT BRAZIL)		
6.35pm	11.35pm	10.35am	10 Mins	🕒 BREAK: SOCIAL HUB AND SCAVENGER HUNT				
6.45pm	11.45pm	10.45am	55 Mins	<ul style="list-style-type: none"> 🕒 - Testimony of PKU patient’s father (global trustee - Brasil) - Testimony of an adult PKU patient (Portugal) - Present and future challenges – moderation: Julio Rocha /Paula Vargas (1) Portugal – Apofen (10 min) (2) Brasil – Safe Brasil (10 min) - Discussion - Closure words 		Ronaldo Lopes Elisabete Almeida Moderation: Dr Júlio César Rocha / DRA Paula R. Vargas (1) Portugal – Apofen: Elisabete Almeida (10 min) (2) Brasil – Safe Brasil: Tania Marini De Carvalho (10 min)		

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AMERICA	EUROPE	AUSTRALIA	EST	GMT	AEDT	DURATION	SPECIAL FEATURED - SPANISH SPEAKING SESSIONS	
TUE 13	TUE 13	WED 14					ON DEMAND CONTENT	
5.00pm	10.00pm	9.00am	12 Hrs	Kids Cartoon Network (in Spanish)		For kids, regarding PKU (diet and blood control), prepared by a group of doctors in Mexico.		
				Fenilcetonuria, salud y nutrición" (PKU: Health and nutrition") (in Spanish)		Agata Bak (Paciente PKU/ PKU Patient)		
				Dieta simplificada: una alternativa para facilitar la vida de las personas con PKU" ("Simplified diet: an alternative to make easier living with PKU") (in Spanish)		M.N. Lizbeth López Mejía		
TUE 13	TUE 13	WED 14					LIVE SESSIONS (2 Hours of Live content)	
6.00pm	11.00pm	10.00am	45 mins	🕒 Presentation & Live Q&A: Fenilcetonuria: desafíos en el seguimiento durante el ciclo vital (Phenylketonuria: challenges in follow-up throughout the life cycle). (in Spanish and English)		🕒 Ma. Jesús Leal Witt, Nutricionista, Msc, PhD. INTA Universidad de Chile Then Prof. Veronica Cornejo (Live Q&A) with Cristian Baigorra, PKU Canada (FACIL)		

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