

2nd

International meeting & Camp on PKU in Morocco

Hotel Zephyr Club Resort and Spa,
Marrakech

Marrakech

17, 18 and 19, November 2023

PROGRAM

"Promoting the health and well-being of individuals with PKU In Morocco through education, communication, and the support of scientific research"

We are honored to announce that the 2nd International meeting and Camp on PKU in Morocco: "Promoting the health and well-being of individuals with PKU in Morocco through education, communication, and the support of scientific research" will be held on November 17 until November 19, 2023 in Marrakech, Morocco.

This workshop and Camp is primarily intended to provide an opportunity for researchers, physicians, practitioners from Industry and Academia, students, and parents to gather and learn about the latest advancements and trends of PKU in Morocco and in the world.

Highlights of the Conference

- A Plenary Forum from a Panel of Leading Experts in PKU and rare diseases.
- Hear and Discuss the Most Exciting Research Discoveries in the field.
- Network with Senior Scientists, Physicians, health Professionals, and Others.
- Look for a New Collaborator

Why Attend?

- Network and Exchange Ideas with Other Professionals
- Work with a Targeted Audience
- Raise Your Profile as a Professional in the rare diseases Field
- Build Your Comprehensive Network
- Visit Marrakech, the city of legends and one of the imperial cities of Morocco.

Topics for the conference

- Newborn screening and PKU situation in Morocco
- Biomarkers in infants/adults with PKU
- New therapies for PKU patients
- Last advances in Science in PKU diagnostic and Treatment: The role of the microbiome in PKU
- International cooperation for PKU follow-up
- Boosting research in PKU treatment and diagnostic
- Inventing low-cost diagnostic and treatment for PKU
- FELSI issues in PKU diagnostic and follow up (Financial, Ethical, Legal, Social issues)
- PKU infant Parents Mental Health
- PKU and Therapeutic exercise
- Growing old with PKU : what can we expect ?
- Finding the right support for parents with PKU
- Long life management of PKU patients

Conference organizers:

Dr. Kamal El Bissati (Chair), Association Marocaine de la Santé de l'Enfant et de la Mère, AMSEM-MAROC
Dr. Mohamed Belkhaty HMEMSA-USA
Mrs. Fatiha Abderrazik, HMEMSA-USA
Mrs. Wafa Bennani, HMEMSA-USA
Mr. Abderrahmane Haddoura, SOS PKU-MAROC
Dr. Mohamed Boutjdir, AMCN-USA

Confirmed Keynote Speakers :

Dr. Khadija Moussayer, Alliance Maladies Rares, Maroc
Dr. Karim Ouldin, Faculté de Médecine et de Pharmacie, Fes
Dr. Amina Barakat, Hôpital des enfants, Rabat
Dr. Annmarie Saarinen, Bloom Standard, USA
Dr. Hassan Ghazal, Université Mohamed VI, Casablanca
Dr. Raquel Yahyaoui Macias, Malaga Regional University Hospital, Spain
Dr. Francis Rossignol National Institute of Health, Bethesda Maryland, USA
Dr. Yamna Kriouil, Ibn Sina Hospital, Rabat
Dr. Faiza Miouet, Gendarmerie Royale Laboratory, Rabat
Dr. Asmae Tantan, Institut National d'hygiène, Rabat
Dr. Abdelhadi Zahouani, CHU Bichat, France
Mrs. Danielle Starin, Rare Disease Institute, Washington, USA
Dr. Kawtar Mashal, Hospital Universitaire Center, Settat
Mrs. Soraia Angiuoli, Children's National Hospital, Washington, USA



Marrakech

17 and 18, November 2023



Scientific Program - Friday, November 17, 2023 9am-5pm

9:00-9:30 AM

Welcome and Opening Remarks, Marrakesh Wali, and other dignitaries, AMSEM, HMEMSA, SOS PKU, Organizing Committee chair
Lessons Learned: Witness Testimony # 1 (Mrs. Fatiha Abderrazik) & Witness Testimony # 2 (Dr. Tazi)

SESSION 1:

Update on the PKU situation in Morocco, Newborn screening, Last advances in Science in PKU diagnostic, FELSI issues in PKU diagnostic

9:30-9:50

La phénylcétonurie au Maroc: Du diagnostic à la prise en charge
Yamna Kriouel, Ibn Sina, Rabat

9:50-10:10

Mise en oeuvre du dépistage neonatal au Maroc: contraintes et défis
Asmae Tantan, Institut National d'hygiène, Rabat

10:10-10:30

Phenylketonuria newborn screening and patient advocacy
Ida Alm-Ndiaye, Revvity, Finland

10:30-11:00 Coffee Break

11:00-11:20

Moroccan Experience of Targeted Screening for Inborn Errors of Metabolism by Tandem Mass Spectrometry
Faiza Meiouet, Gendarmerie Royale, Rabat

SESSION 2:

New therapies for PKU patients, last advances in treatment; the role of microbiome, Nutrition

11:20-11:40

Traitement de la phénylcétonurie: nouvelles avancées
Francis Rossignol, National Human Genome Research Institute (NHGRI), National Institutes of Health, USA

11:40-12:00

Microbiome and rare diseases
Hassan Ghazal, Université Mohamed VI, Casablanca

12:00-12:20

DADFMS : une nouvelle solution réglementaire pour la prise en charge des produits nutritionnels des personnes avec PKU au Maroc
Abdelhadi Zahouani, CHU Bichat, Paris

12:20-13:40 Lunch

13:40-14:00

Defining the importance of early diagnosis and the initiation of a strict diet for pku children by providing essential amino acids along with a low protein diet.
Danielle Starin, Rare Disease Institute, Washington, USA

SESSION 3:

International cooperation for PKU/rare diseases follow up

14:00-14:20

Problématique générale des maladies rares au Maroc
Khadija Moussayer, Alliance Maladies Rares, Maroc

14:20-14:40

Newborn Screening in Morocco: past, present and future
Karim Ouldime, Faculté de Médecine et de Pharmacie, Fes

14:40-15:00

Building a Multidisciplinary Team Approach in PKU Newborn Screening
Raquel Yahyaoui Macias, Hospital Regional Universitario de Malaga

15:00-15:20

Development of a simple and effective PCR-based assay to detect mutations in a similar metabolic rare disease: prospects for future scientific international collaborations
Aziz A. Chentoufi, SKLM, Ottawa. Canada

15:20-15:45

Point of Care tests for newborns
Anmarie Saarinen, Bloom Standard, USA

15:45-16:05 : Coffee Break

16:05-17:00 : Poster presentations - Wrap up sessions

17:30-23:00 : Visit some historic sites in the city with a dinner at the medina.

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Marrakech

17 and 18, November 2023



PKU Family Camp - Saturday, November 18, 2023 10am-3pm

10:00-13:00

Workshop 1: PKU infant Parents Mental Health

Kawtar Mashal, Hospital Universitaire Center, Settat
Laila Lekfy Filali, Escalade-School, Association de Bienfaisance
Dr. Filali, educational psychologist and expert committed to supporting early childhood and adolescents will provide holistic support to mothers whose children are dealing with mental health issues. her goal is to empower mothers by helping them understand and manage the situation in a way that promotes the well-being of the child and the family.

Workshop 2: Finding the right nutrition for PKU patients

Francis Rossignol, National Institute of Health, Bethesda Maryland, USA

Danielle Starin, Rare Disease Institute, Washington, USA

Danielle Starin, Dietitian-Nutritionist at the Rare Disease Institute in Washington, USA, will collaborate with **Dr. Francis Rossignol**, a Geneticist from the NIH Clinical Genetics department, as a PKU team specialist. They will:

- Manage several PKU case studies that require comprehensive health check-ups.
- Provide training and share their expertise with pediatricians, pediatric neurologists, nutritionists, and dietitians on the latest advancements in PKU screening and therapy.

Workshop 3: Improving PKU Patients quality of life and facilitating effective communication

Firdaouss Kmir, a health professional specializing in diagnosing and treating communication disorders. Her work improves the quality of life of children with difficulties related to language delay by helping patients overcome communication and swallowing disorders, thus facilitating effective communication. She provides personalized care and support to clients of all ages in various clinical and educational settings.

13:00-15:00 Lunch

Workshop 4: Cooking Demo sessions with PKU parents

Mme Najia Hebbazi in coop with **Mme Nezha Bourass** and **Mme Fatime Zahra** will manage cooking demo session with all parents

Workshop 5: Healthcare Q&A Sessions:

Question and answer sessions where parents can ask healthcare specialists about children's health and development. This can cover topics like nutrition, is there any Therapies needed, Brain function....

20:00-1:00am Dinner, Reception

Conference Gala dinner with traditional Moroccan folklore
Traditional music and costumes from Marrakech
Awards ceremony

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Please register through the website: <https://www.pkumaroc.com/>

For any assistance/help, please do not hesitate to contact us at: infos@pkumaroc.com

We appreciate your time and consideration and look forward to seeing you soon.

We hope you are able to join us for these events; and if there are people in your network who you think would be interested, please don't hesitate to share the flyer and information far and wide!

Thank you



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