الجمهورية الجزائرية الديمقراطية الشعبية
PEOPLE'S DEMOCRATIC REPUBLIC OF ALGERIA

وزارة الصحة
MINISTRY OF HEALTH

معًا، من أجل الأمراض النادرة في الجزائر
Together, for rare diseases in Algeria

الجزائر و الأمراض النادرة
ALGERIA RARE DISEASES

البرنامج

يوم الإثنين **20** ماي **2024**
فندق الأوراسي - الجزائر العاصمة - **قاعة ألوان**

Programme

الجزائر و الأمراض النادرة
ALGERIA RARE DISEASES

08.00 - 08.30	Accueil des participants
08.30 - 08.45	Cocktail de bienvenue
08.45 - 09.00	Mot de bienvenue Pr. L. RAHAL - Algérie D.G des Services de Santé et de la Réforme Hospitalière
09.00 - 09.20	Discours & Ouverture officielle Monsieur le Ministre de la Santé
09.20 - 09.50	Prise en charge des maladies rares en Algérie : État des lieux Pr. A. TEBAIBIA - Algérie
09.50 - 10.00	Actualisation de la liste des maladies rares : Texte réglementaire Dr. L. BENBERNOU - Algérie
10.00 - 10.20	Circuit de prise en charge d'une maladie rare : Documentaire
10.20 - 10.45	Prise en charge des maladies rares en Algérie : Cas de l'hémophilie Dr. S. NEKKAL - Algérie
10.45 - 11.05	Maladies rares : Exemple d'un pays Arabe Pr. M. ZAKI - Egypte
11.05 - 11.25	Maladies rares : Exemple d'un pays d'Europe Pr. A. LINGLART - France
11.25 - 11.40	Maladies rares : Exemple d'un pays d'Europe Pr. L. SERVAIS - Angleterre
11.40 - 12.30	Discussion & Clôture

Déjeuner

Biographie

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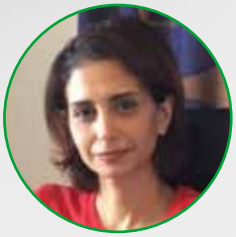
ALGERIA RARE DISEASES



Amal Nassima OULHISSANE épouse OMAR
Maladies neuromusculaires service de Pédiatrie
CRMR - RPC

Dr. OULHISSANE OMAR Amel is a renowned pediatric specialized in neuromuscular diseases. She is a member of the French Reference Network for Rare Neuromuscular Diseases (RPC). She has contributed to the many publications include "Multidisciplinary Management of Duchenne Muscular Dystrophy" in Archives de Pédiatrie (2023), "Evaluation of the Efficacy of Novel Gene Therapies in Spinal Muscular Atrophy" in Revue Neurologique (2022), and "Prognostic Factors in Hereditary Peripheral Neuropathies in Children" in Médecine et Maladies Infectieuses (2021).

Dr. OULHISSANE has also contributed to reference books such as "Practical Guide to Pediatric Neuromuscular Diseases" (Lavoisier Editions, 2020, co-author) and "Management of Rare Diseases in Pediatrics" (Doin Editions, 2018, contributor).Within the RPC, she serves as the Coordinator of the "Muscular Dystrophies" working group, a Member of the steering committee of the RPC Neuromuscular Diseases, and an Organizer of continuing education for healthcare teams.

Dr. OULHISSANE is a recognized expert in the management of pediatric neuromuscular diseases. Her research work and involvement in the RPC have helped improve knowledge and clinical practices in this complex field of pediatrics.

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Pr. Maha Zaki MD, PhD
Clinical Genetics, Pediatrics
Cairo, Egypt

Prof. Maha Zaki is a Professor in the Clinical Genetics Department at the Human Genetics & Genome Research Institute, National Research Centre. She received the State Appreciation Award in Science from President El Sisi on Education Day in 2019. She has been working in the field of human genetics since joining the center in 1986. After receiving her PhD in pediatrics in 2008, she specialized in the field of clinical genetics, especially neuro- genetics.

She has published about 135 research papers in international journals, many of which have led to the discovery of a large number of genes that have greatly helped reduce genetic diseases. She also received the State Award for Scientific Excellence in 2011, and the State Award for Scientific Excellence in Advanced Science and Technological Sciences in 2018.

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Agnes Linglart (AP-HP)
University Paris Saclay
Assistance Publique des Hôpitaux
Paris, France

Professor of Paediatrics @ Paris Saclay University, AP-HP, Le Kremlin Bicêtre, FRANCE.
Vice-dean for International Affairs and Europe @ Paris Saclay University - Faculty of medicine.
Head of the department of paediatric endocrinology and diabetes for children @ the Paris Saclay hospital.
Head of the department of adolescent medicine @ the Paris Saclay hospital.
President of the Research Steering Committee (CRLBS) @ the Paris Saclay hospital.
Expert in pediatric endocrinology and metabolic bone diseases.
Pilot for the 4th National Plan for Rare Diseases (PNMR4).
National Coordinator of the Reference Center for Rare Disorders of the Metabolism of Calcium and Phosphate: https://youtu.be/WJYr7uR_kCs
National coordinator of the French Rare Bone Disease Network “OSCAR”.
President of the French Society of Pediatrics (SFP).
Chair of the Main thematic group 2 Calcium Phosphate @ Rare endocrine diseases ERN.
Chair of the Strategic and Finance committee @ the European Society of Pediatric Endocrinology.

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Laurent Servais, MD, Ph
University of Oxford, UK,
and University of Liège, Belgium

Laurent Servais is Professor of Paediatric Neuromuscular Diseases at the University of Oxford in the UK, and invited Professor at the University of Liège in Belgium. He graduated in medicine and pediatrics from the University of Louvain (in Louvain-la-Neuve and Brussels in Belgium) then trained as a child neurologist in the Robert Debré Hospital in Paris, France, and as a myologist at the Institute of Myology, Pitié-Salpêtrière University Hospital, Paris.

Professor Servais' main research interests cover innovative outcome measures and clinical trials design and newborn screening (NBS). He has been involved as Principal Investigator in several clinical trials in spinal muscular atrophy (SMA), Angelman Syndrome X-linked myotubular myopathy, and Duchenne muscular dystrophy (DMD), and in leading the NBS program for SMA NBS in Belgium and in the UK. He is the coordinating investigator of two large natural history studies in Angelman in the UK and in Belgium that aims to identify and validates innovative outcome measures and biomarkers

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Amar TEBAIBIA
Faculty of Medicine of Algiers
head of the internal medicine department
of the public hospital establishment of El Biar

TEBAIBIA AMAR is a professor of internal medicine at the Faculty of Medicine of Algiers and head of the internal medicine department of the public hospital establishment of El Biar. Professor TEBAIBIA AMAR is president of the Algerian society of obesity and metabolic diseases, he is the past president (2016-2021) and honorary president of the Algerian society of internal medicine. He is the founder of the Algerian journal of internal medicine and director of its publications for six years.

He is a reviewer in national and international journals, and a member of the reading committee of the several national and international conferences. He is the chairman of the national committee of clinical experts, and an expert for several organizations and institutions. He was the coordinator of the long covid-19 care guide, the diabetic foot care guide, management of obesity guide and leader of several research projects. He has more than 500 communications and scientific publications in national and international congresses and journals.

Professor Amar Tebaibia is particularly interested in metabolic diseases, Non-alcoholic fatty liver disease, rare diseases, microbiota and diseases of the digestive system.

Biographie

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ALGERIA RARE DISEASES

MEKKI AZZEDINE

Docteur en Médecine générale - 1989
Diplôme d'Etudes Médicales Spécialisées en Pédiatrie - 1995
Diplôme Inter Universitaire en Epileptologie (France 2002)
Diplôme Inter Universitaire en Neurophysiologie clinique (France 2004)
Diplôme Inter Universitaire en Maladies Héréditaires du Métabolisme (France 2006)
Doctorat en Sciences Médicales - 2013
Professeur en pédiatrie - 2014
Chef de service intérim de Pédiatre, Service Pédiatrie, CHU Hussein Dey, Alger 2014 – 2017
Chef de service Titulaire, Service de Pédiatrie, CHU Hussein Dey, Alger 2019

RESPONSABILITES PEDAGOGIQUES

Président du Comité Pédagogique Régional de Spécialité (CPRS Centre de Pédiatrie) 2023
Président du Comité Pédagogique National de Pédiatrie (CPN)2023

SOCIETES SAVANTES

Membre de la Société Algérienne de Pédiatrie (SAP)
Responsable du comité Maladies Héréditaires du Métabolisme (SAP)
Responsable du comité Neurologie Pédiatrique (SAP)
Membre de la Société Française de Neurologie Pédiatrique (SFNP)
Membre de la Société Européenne de Neurologie Pédiatrique (SENP)
Membre de la Société Française des Maladies innées du Métabolisme (SFEIM)
Vice Président de la ligue Algérienne contre l'Epilepsie (LAPE)

Notes :

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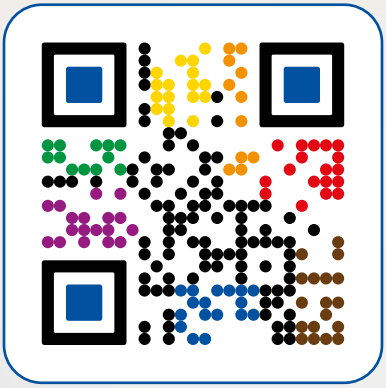
إمسح الرمز التالي



لتحميل البرنامج