

4th Caribbean Reference  
Centers Days for Rare and  
Orphan Diseases

**JCMO 2024**  
14-15-16 November 2024

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**EPILEPSY SOCIETY**  
OF THE CARIBBEAN

## PROGRAM PREVIEW

Hotel Karibea Saint-Luce

from November 13 to 16, 2024

### Scientific Committee

Rémi BELLANCE  
Elisabeth SARRAZIN  
Cyril GOIZET  
Guilhem SOLE  
Aïssatou SIGNATE  
Sophie DUCLOS  
Anna-Gaëlle GIGUET-VALARD  
Nicolas GAROFALO-GOMEZ  
Ignacio ANTOLIN  
Oriane ALLARD SAINT-ALBIN  
Maël CANTACUZENE

### Organizing Committee

Elisabeth SARRAZIN  
Rémi BELLANCE  
Aïssatou SIGNATE  
Sophie DUCLOS  
Anna-Gaëlle GIGUET-VALARD  
Micheline WILTORD  
Maël CANTACUZENE  
Alida FARDINI  
Lina HARMENIL  
Ignacio ANTOLIN  
Oriane ALLARD SAINT-ALBIN

## Wednesday, November 13th - WELCOME

From 20h30 : Welcome cocktail

# Thursday, November 14th - INTERFACE DAY – JCMO/ECS

## 08h30–09h00: Opening

08h30-08h45: Jérôme LE BRIERE - General Manager of the University Hospital of Martinique (CHUM), Rémi BELLANCE (CERCA)  
08h45-09h00: Anne-Sophie LAPOINTE (DGOS)

## 09h00-13h00: Epilepsy

*Moderators: Amza ALI and Gaetan LESCA*

09h00-09h15: Opening - Dave CLARKE (Texas), Amza ALI (Jamaïque), Remi BELLANCE (Martinique – JCMO host)

09h15-09h30: Epilepsy and developmental disorders – teleconference Dave CLARKE

09h30-10h00: Epilepsy care in developing countries: Challenges in Common and potential Solutions - Amza ALI

10h00-10h30: Organization and challenges of epilepsy care in the Eastern Caribbean – Christian LASHORN

*10h30–11h00 - break*

11h00-11h30: Drug-resistant pediatric epilepsy in 2 Caribbean hospital populations - Nicolas GAROFALO-GOMEZ

11h30-12h00: Psychiatric comorbidities in epilepsy - Bertrand DE TOFFOL

12h00-12h30: Drug-resistant epilepsies “Avoiding therapeutic nihilism” - Albert COLON

*12h30-13h00 - poster tour*

*13h00-15h00 - lunch*

## AFTERNOON

## 15h00-16h30: How to diagnose NMD in 2024

*Moderators: Yann PEREON and Rémi BELLANCE*

15h00-15h20: Clinic - Emmanuelle CAMPANA-SALORT

15h20-15h35: Electrophysiology - Ruben BLANCO DIAZ

15h35-15h50: Anatomopathology – Marie Laure MARTIN-NEGRIER

15h50-16h05: Imaging - Pascal CINTAS

16h05-16h20: Genetics - Mireille COSSEE

16h20-16h30: Round table discussion

*16h30-17h30 - poster tour*

17h30: closing of the day

## Paramedical parallel session

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Thursday, November 14th

8h30- 16h30

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### « Motor Function Measurement » (MFM) course

Free certification training, both theoretical and practical, provided by a trainer from Lyon University Hospital, with the support of the BIOGEN laboratory.

The **Motor Function Measurement (MFM)** is a quantitative scale used to measure motor function in children and adults suffering from neuromuscular disorders. It requires certification training.

**Regardless of the diagnosis and extent of motor deficiencies, MFM allows to:**

**Clarify** the symptomatology and evolution of neuromuscular diseases

**Objectivize** the impact of therapeutic measures

**Guiding** rehabilitative and adaptive measures

**Facilitating** communication between the various parties involved in the care process

**Select** homogeneous groups of patients for therapeutic trials

*10h30–11h00 – break*

*12h00-15h00 - lunch*

## Friday, November 15th - MUSCLE

### 09h00-10h30: MYASTHENIA (ALEXION SYMPOSIUM)

*Moderators: Guilhem SOLE and Bertrand DE TOFFOL*

09h00-09h20: Autoimmune myasthenia: diagnostic strategies in 2025 - Emmanuelle - CAMPANA-SALORT

09h20-09h40: Most recent local epidemiological data - Sophie DUCLOS

09h40-10h00: Management of autoimmune myasthenia in 2025 - Yann PEREON

10h00-10h30: Emergency treatment in NMOSD - Hugo CHAUMONT

*10h30-11h00 break and poster tour*

### 11h00-12h30 (or 13h00): Open communications

*Moderators: Nicolas GAROFALO and Emmanuelle CAMPANA-SALORT*

11h00-11h15: Epidemiological, clinical and paraclinical study and management of chronic inflammatory demyelinating polyneuropathy (CIDP) in the neurology department of the CHU of Martinique - Abdoulaye TAMEGA

11h15-11h30: Long-term effects of patisiran on survival and cardiac parameters in patients with transthyretin-related cardiac amyloidosis: Post hoc analysis of APOLLO-B and APOLLO OLE cardiac subpopulation (open-label extension studies) - Jocelyn INAMO

11h30-11h45: Juvenile dermatomyositis - Arthur FELIX

11h45-12h00: An anesthetic mishap leading to a diagnosis of Sodium Channel Myotonia - Avidesh PANDAY

12h00-12h15: Small and large fiber neuropathies, physiological explorations in the case of amyloidosis - Sylvie MECHARLES

12h15-12h30: Three cases of rabies mimicking Guillain-Barre syndrome - Nathalie DESCHAMPS

12h30-12h45: Electrophysiological characterization of Hereditary Sensory and Autonomic Neuropathy type III - Joël GUTIERREZ

12h45-13h00: Functional swallowing disorders in neuromuscular diseases, assessment, prevention and guidance - Aina RAKOTOMANANJO and Bénédicte GO

*13h00-14h00 - lunch*

### 14h00-15h30: SYMPOSIUM AMYLOSE with the support of ALNYLAM

*Moderators: Remi BELLANCE and Jocelyn INAMO*

14h00-14h30: Amylose specificity in the Caribbean - Aissatou SIGNATE

14h30-15h00: Neurological updates in amylose - Guilhem SOLE

15h00-15h30: The latest in cardiology therapeutics - Jocelyn INAMO

*15h30-16h00 Break and poster tour*

### 16h00-17h30: Inflammatory neuropathies

*Moderators: Andoni URTIZBEREA and Avidesh PANDAY*

16h00-16h20: Node of Ranvier pathologies - Sharam ATTARIAN

16h20-16h35: Arboviruses - Sandrine PIERRE-FRANCOIS

16h35-16h50: Guillain-Barré syndrome in the French West Indies: what are the specifics? - Aissatou SIGNATE

16h50-17h10: Peripheral neurological complications of cancer immunotherapy - Laurent MAGY

17h30: closing of the day

**20h00: « GALA » EVENING** (*casual*)

## Paramedical parallel session

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**Friday, November 15**

**8h30- 12h30**

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### **Adapted physical activity in neuromuscular diseases**

08h30–09h00: Welcome

09h00-09h30: Medical presentation: Specificity of pediatric care in neuromuscular diseases - Simon TOURNIER - MPR, CHU Guadeloupe

09h30-10h00: Impact of respiratory diseases and adapted physical activities, Caribbean experience - Maria ESCRIBANO PEREZ - Physiotherapist, CHU Martinique

10h00-10h30: Disability-Adapted sports activities - Sandro LAUPA - APA

*10h30-11h00 - Break*

11h00-12h30: A plea for adapted physical activity in neuromuscular diseases - Léonard FÉASSON - St Etienne University Hospital

*13h00–14h00 - Lunch*

## Saturday, November 16th– NEUROGENETICS

### 09h00-10h10: French National Plan for Rare Diseases – Brain Team – PNMR4

*Moderators: Léonard FÉASSON and Cyril GOIZET*

09h00-09h15: AFM-Téléthon's innovative assistance model

09h15-09h35: Reference Platforms for Rare Diseases - Maryse ETIENNE-JULAN, Narcisse ELANGA et Remi BELLANCE

09h35-10h10: Round table discussion – French National Plan for Rare Diseases, Filières, PNMR4, ERN

*10h10-10h30 - Break and poster tour*

### 10h30-11h40: Genetics & Neurovascular

*Moderators: Hugo CHAUMONT and Anna-Gaëlle GIGUET VALARD*

10h30-11h00: Hereditary cerebral vasculopathy - Monogenetic causes - Aissatou SIGNATE

11h00-11h30: Variants in 5'UTRs altering anticipatory reading frames: impact on the genetics of rare and common neurovascular diseases - David-Alexandre TREGOUET

11h30-11h40: Round table discussion: Questions and Answers

### 11h40-13h10: Symposium JCMO Latest in Rare Diseases with the support of BIOGEN

*Moderators: Guilhem SOLÉ and Elisabeth SARRAZIN*

11h40-12h10: Spinal muscular atrophy (SMA) patients, from pathophysiology to management - Pascal CINTAS et Elisabeth SARRAZIN

12h10-12h40: Where are we in the care of ALS patients? - Sophie DUCLOS

12h40-13h10: Friedreich's ataxia: pathophysiology, clinical features and organization of care - Cyril GOIZET

*13h10-14h15 - lunch*

### 14h15-16h00: Neurogenetics in 2024: the genome and beyond

*Moderators: Jacqueline BIRD-COMPTON and Narcisse ELANGA*

14h15-14h45: Epilepsy and Genome - Gaëtan LESCA

14h45-15h15: Explaining clinical variability: the example of spino-cerebellar degeneration - Giovanni STEVANIN

15h15-15h45: FSHD: an example of an epigenetic disorder - Karine N'GUYEN

15h45-16h00: Questions and Answers

## 16h15 – CLOSING OF THE CONGRESS

## Our partners

