ICNMD 2022
17TH INTERNATIONAL CONGRESS ON NEUROMUSCULAR DISEASES
5 - 9 July 2022 Brussels, Belgium

Patients day 05/07/2022
9u - 16u30

Congreszaal - Salle de congres Square
Ravensteinstraat - Rue Ravenstein 2
1000 Brussel - Bruxelles

Inschrijven via - Inscription par website: https://icsevents.eventsair.com/icnmd-2022/patients-day
Hybride evenement (fysiek of virtueel) - Événement hybride (en présentiel ou virtuel)
Simultane vertaling voorzien ter plaatse - Traduction simultanée prévue sur place Nl/Fr - Fr/Nl

Programma - programme

Voormiddag - Matinée (moderator: prof.dr. Véronique Bissay - dr. Ann Cordenier)

09u - 09u10	Inleiding - Introduction
09u10 - 09u45	**Du gène (la recette) à la protéine (le gâteau): comprendre les maladies génétiques** (Genetische aandoeningen eenvoudig uitgelegd) Prof. dr. Alexandra Belayew, Université de Mons, Belgique (sur proposition de l'ABMM)
09u45 - 10u20	**Stratégies thérapeutiques dans la FSHD: maîtriser DUX4 et le stress oxydant, sans oublier les exercices musculaires** (Behandeling van FSHD) Prof. dr. Alexandra Belayew, Université de Mons, Belgique (sur proposition de l' ABMM)
10u20 - 10u45	**Pauze - Pause**
10u45 - 11u20	**L'amyotrophie spinale disparait progressivement de Belgique Francophone… Et maintenant, si nous faisions 120 fois mieux?** (SMA, een uitdovende ziekte in Franstalig België .. En als we nu 120 keer beter zouden doen?) Prof. dr. Laurent Servais, University of Oxford, United Kingdom & Université de Liège, Belgique & Madame Tamara Dangouloff, Chef de project screening SMA, Université de Liège, Belgique
11u20 - 11u55	**Federale financiële en fiscale voordelen voor personen met een beperking** (Aides financières pour les personnes en situation de handicap en Belgique) Mijnheer Alexander Leysen (Spierziekten Vlaanderen)
11u55 - 12u35	**European Neuromusculair Center (ENMC): à l'initiative de et pour les patients et leurs familles** (ENMC: een initiatief van en voor patiënten met een spierziekte en hun families) Prof. dr. Alexandre Méjat, Chair de ENMC
12u35	Dankwoord - Mots de remerciement

Namiddag - Après-midi (moderator: prof.dr. Véronique Bissay - dr. Ann Cordenier)

13u30 - 13u40	Inleiding - Introduction
13u40 - 14u15	**Ondersteuning van de levenskwaliteit bij amyotrofe lateraal sclerose (ALS)** (Les soins de support pour assurer une qualité de vie des patients atteints de SLA) Mevrouw Evy Reviers (CEO & chairwoman ALS-liga) & Mevrouw Liesbet Casier (ALS Liaison, ALS-liga)
14u15 - 14u50	**Wat is chronische inflammatoire demyeliniserende polyradiculoneuropathie (CIDP)?** (Qu'est-ce que la polyradiculoneuropathie inflammatoire démyélinisante chronique (PIDC)?) Prof. dr. Peter Van den Bergh (Université Catholique de Louvain, België) (op voorstel van Spierziekten Nederland)
14u50 - 15u15	**Pauze - Pause**
15u15 - 15u50	**Het Charcot-Marie Tooth (CMT) onderzoek: stand van zaken** (Dernières avancées dans la recherche sur les neuropathies héréditaires de Charcot-Marie-Tooth) Prof. dr. Vincent Timmerman (Universiteit Antwerpen, België) (op voorstel van ECMTF)
15u50 - 16u25	**La prise en charge des malades dans leur vie de tous les jours: la stratégie de l'ABMM** (Zorg voor patiënten in hun dagelijks leven: de strategie van de ABMM) Monsieur Jean-Marie Huet (président de l'ABMM, Belgique)
16u25	Dankwoord - Mots de remerciement

Biografieën van sprekers - biographies des orateurs

Alexandra Belayew

Following a MSc in Chemistry and a Ph.D. in Biochemistry, Alexandra Belayew moves to the USA for a 2-year post-doctoral stay in Molecular Biology at the Fox Chase Cancer Center under Shirley Tilghman's supervision. That is where she discovers the major theme of her future research projects: the regulation of gene expression. Back to Belgium A. Belayew heads a group of researchers in Joseph Martial's laboratory (ULiège ; 1982-1993), then in Désiré Collen's department (KULeuven ; 1994-1999) where she hypothesizes that the DUX4 gene discovered in her team causes the FSHD myopathy. In 1999 she becomes head of the Molecular Biology laboratory (Faculty of Medicine and Pharmacy) at the University of Mons (UMONS) where she teaches Biochemistry and Molecular Biology (until 2015). Her team is co-directed with Frédérique Coppée, and studies DUX4 and the molecular mechanisms of FSHD; they have developped therapeutic strategies in collaboration with Steve Wilton. This research is funded by patient associations from different countries.
Alexandra is co-author of about 100 peer-reviewed publications

Laurent Servais

Laurent Servais, MD, PhD is professor of paediatrics neuromuscular diseases at the University of Oxford and invited Professor at the University of Liege, Belgium. He graduated from the University of Louvain (Medicine) and Brussels (Paediatrics), and trained as a child neurologist in Robert Debré Hospital (Paris) and as a myologist in the Institute of Myology, in La Pitié Salpétrière (Paris). His main research interests cover innovative outcome measures and clinical trials design and newborn screening. He has been involved as PI in several clinical trials in spinal muscular atrophy, X-Myotubular Myopathy and Duchenne Muscular Dystrophy, and in leading the pioneering newborn screening program for spinal muscular atrophy in Belgium and in the UK. He is the leader of the ambitious "Baby detect" programs, that aims to screen at birth 120 treatable severe conditions of children.

Tamara Dangouloff

Tamara Dangouloff has a PhD in health economics on the medico-economic analysis of newborn screening for SMA. She trained as a children's nurse and later as head nurse in paediatrics. She is project manager of the newborn screening program for SMA in Belgium and she has been involved in several projects in the field of SMA. She is working at the University of Liège on the ambitious "Baby detect" programs, that aims to screen at birth 120 treatable severe conditions of children.

Alexander Leysen

Vice-president patient organisation "Spierziekten Vlaanderen".
Diagnosis responsible CMT (Charcot Marie Tooth disorder).
For 25 years Alexander has been working as a volunteer for people with a neurological muscle disorder and more specifically CMT. As an experienced expert he knows the many practical problems people with disabilities are confronted with. He has studied federal legislation and social security for PMH and has repeatedly given information sessions on this subject.

Alexandre Méjat

Personally affected by a Bethlem myopathy, Alexandre MEJAT, is a member of the Executive committee of ENMC since November 2015 and is the current ENMC Chair. PhD in molecular and cellular biology by training, Dr Méjat has been working on neuromuscular junction defects and Emery Dreifuss muscular dystrophy in France and USA. He led a research group in Lyon during 8 years before becoming Scientific International Affairs manager for AFM Telethon.He is now implicated in several international networks and rare diseases consortia such as the ERN-EuroNMD, European Joint Program on Rare Diseases (EJP-RD) and the International Rare Diseases Research Consortium (IRDiRC), actively promoting both scientific collaboration and patient involvement at all steps of Research

ALS Liga België vzw

The ALS League Belgium is a non-subsidised non-profit organisation whose mission is to look after the interests of ALS patients both nationally and internationally. On a national level, we offer free professional care and support, physically (via our aids work, ALS Mobility & Digitalk vzw), mentally and socially. We focus on ALS patients, their relatives and all parties involved and achieve this by raising public awareness and by financing and stimulating scientific research. Furthermore, we offer free of charge the services of the ALS Liaison to support the patient, his/her relatives and care providers in order to create an optimal home situation with the goal of allowing the patient to stay at home for as long and as qualitatively as possible.

Peter Van den Bergh

Peter Van den Bergh is Full Professor (emeritus) at the University of Louvain, Brussels, Belgium. Fascinated by neuromuscular diseases, he obtained a grant from the ALS Foundation USA to do research on ALS and muscle and nerve pathology at USC in Los Angeles and at Tufts New England Medical Center in Boston. He is certified in electrodiagnosis by the Board of the Amercian Association for Neuromuscular and Electrodiganostic Medicine (AANEM).
In 1999, he created he Neuromuscular Reference Center at the University Hospital Saint-Luc in Brussels and received the Center of Excellence label from the GBS/CIDP Foundation International in 2018. He is a member of Euro-NMD and co-chairs the Euro-NMD neurophysiology group. His main areas of research are inflammatory neuropathies, electrodiagnosis and functional assessment scales in neuromuscular patients. He is the author of more than 180 peer-reviewed publications. He is the immediate past-chair of the Inflammatory Neuropathy Consortium of the Peripheral Nerve Society and he holds or has held leadership positions in the Belgian Neurological Society, the Belgian-Dutch Neuromuscular Study Group, the World Muscle Society, the European Academy of Neurology, the Belgian Association against NeuroMuscular Diseases (ABMM) and the Peripheral Nerve Society. He is a fellow of the European Academy of Neurology (FEAN) and of the Amercan Academy of Neurology (FAAN).

Vincent Timmerman

Prof. Vincent Timmerman is a biologist and Full Professor at the University of Antwerp, Belgium, and head of the Peripheral Neuropathy Research Group of the Faculty of Pharmaceutical, Biomedical and Veterinary Sciences since 2002. He won several research prizes for his pioneering work in identifying novel loci and genes for Charcot-Marie-Tooth disease (CMT) and related neuropathies. He published more than 200 peer-reviewed papers and chapters in textbooks. He has supervised a great number of postdocs, PhD students and students working in this expert area. Vincent has been the organizer of the International CMT Consortium meetings for many years and is a member of different scientific advisory and evaluation boards. His research is currently focused at understanding the biological consequences of mutant genes associated with peripheral neuropathies, and how this knowledge can be translated towards the development of therapeutic strategies.

Jean-Marie Huet

Jean-Marie HUET is the President of the Belgian Association against Neuromuscular Diseases, he is himself affected by a neuromuscular disease. He is also a member of the Conseil Supérieur National des Personnes Handicapées, of the Comité Handicap de l'AViQ and he is very active in the defence of the rights of people with disabilities.

Wij danken de deelnemende patiëntenorganisaties van deze dag:
Nous remercions les organisations de patients participantes de cette journée:

Wij danken ook onze sponsors die het mogelijk maken deze dag te realiseren:
Nous remercions également nos sponsors qui nous ont permis de réaliser cette journée: