43ÈME RÉUNION DE LA SOCIÉTÉ EUROPÉENNE DE NEUROLOGIE PÉDIATRIQUE

43RD SENP MEETING

PROGRAMME ET INFORMATIONS GÉNÉRALES
PROGRAM AND GENERAL INFORMATION

17-19 SEPTEMBRE 2015

SEPTEMBER 17-19, 2015

MAISON DES ASSOCIATIONS INTERNATIONALES

BRUXELLES - BELGIQUE

BRUSSELS - BELGIUM

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BIENVENUE À BRUXELLES

WELCOME to Brussels

Chers amis,

Au nom du bureau de la Société Européenne de Neurologie Pédiatrique et du comité organisateur, nous avons le plaisir de vous accueillir à Bruxelles pour la 43ème réunion de la SENP.
Tout au long de ce congrès, deux thèmes principaux seront développés : les maladies neuromusculaires et les maladies héréditaires du métabolisme. Nous remercions chaleureusement les orateurs qui ont accepté de partager leur expérience et leur expertise dans ces deux domaines en pleine expansion. Le cours précédant le congrès est dédié à la neurologie néonatale. Les jeunes confrères neuropédiatres sont vivement encouragés à participer à cette conférence.
Bruxelles est une ville assurément cosmopolite où toutes les langues et toutes les cultures se rencontrent. Le développement des institutions européennes et d'organisations internationales ont renforcé son caractère multiculturel, un terreau idéal où s'opère un brassage des nationalités, des idées et des modes de vie. Bruxelles est à tout le monde, c'est pour cette raison que chacun s'y sent chez soi. Le lieu du congrès, la Maison des Associations Internationales, reflète bien ce caractère.
Nous vous attendons nombreux pour des échanges scientifiques fructueux, des discussions animées et confraternelles sans oublier une découverte de Bruxelles.
A bientôt, à Bruxelles

Marie-Cécile Nassogne,
Présidente du Congrès

Dear friends,

On behalf of the SENP board and the organizing committee, we are pleased to welcome you to Brussels for the 43rd SENP meeting..
Throughout this conference, two main topics will be discussed: neuromuscular diseases and hereditary metabolic diseases. We heartfully thank the speakers who agreed to share their experience and expertise in these two developing fields. The workshop given before the conference is dedicated to neonatal neurology. We encourage our young neuropediatrician colleagues to attend it.
Brussels is a cosmopolitan city where lots of languages and cultures meet. The great amount of European institutions and international organizations have reinforced its multicultural nature. Brussels belongs to everyone, which is why everyone feels at home in this city. The International Associations House, the place where the congress is held, reflects this characteristic really well.
We look forward to seeing many of you in order to have interesting scientific exchanges, lively discussions between peers and, of course, a wonderful visit of Brussels.
See you soon in Brussels,

Marie-Cécile Nassogne
Congress president

Je joins mes souhaits de bienvenue à ceux exprimés par Marie-Cécile Nassogne.
Cette année, nous avons introduit plusieurs nouveautés dans le congrès : nous offrons l'inscription au congrès à une quinzaine de neuropédiatres de moins de 35 ans, nous avons programmé une session « Meet the Expert » dont le sujet sera l'épilepsie et nous avons organisé une session « Projets de recherche en cours ». Aussi, nous restons très attachés à notre spécificité qui est la possibilité de discuter et de présenter de manière amicale et conviviale, de faciliter les échanges. C'est dans cet esprit que nous avons organisé notre réunion annuelle et que nous nous réjouissons de vous accueillir à Bruxelles.
Au nom du Bureau, j'ai le plaisir de vous souhaiter à tous un excellent congrès.

Patricia Leroy
Présidente SENP

I join my welcome wishes to Marie-Cécile Nassogne's.
This year, we have introduced some novelties in the conference: we offer the complimentary registration fees to around fifteen neuropaediatricians under the age of 35, we have planned a session named «Meet the Expert» which will have epilepsy as a topic, and we have organized a session named «Ongoing research project». Furthermore, we remain true to our specificity which is the possibility to talk about and present subjects in a friendly and warm manner, and foster scientific exchanges. It's in this spirit that we have organized our annual meeting and we are looking forward to welcoming you in Brussels.
In the name of the Bureau, I'm happy to wish you all a wonderful conference.

Patricia Leroy
SENP President

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PLANNING / AGENDA

JEUDI 17 SEPTEMBRE / THURSDAY, SEPTEMBER 17TH

COURS : NEUROLOGIE NEONATALE / Course: Neonatal neurology

13:30	Aspects cliniques / Clinical approach
16:00	Explorations complémentaires / Complementary investigations
19:00	CONFERENCE INAUGURALE GILLES LYON / Introduction lecture Gilles Lyon
20:00	Cocktail dînatoire / Reception

VENDREDI 18 SEPTEMBRE / FRIDAY, SEPTEMBER 18TH

08:00	Accueil / Welcome
08:30	MALADIES NEUROMUSCULAIRES / Neuromuscular diseases
10:30	**Communications Orales** / Oral communications
12:00	SYMPOSIUM PTC / PTC Symposium
14:00	CONFERENCES / Plenary sessions
16:00	**Communications Orales** / Oral communications
17:00	Projets de recherche / Research projects
18:00	Assemblée Générale de la SENP / SENP General Assembly
19:30	Soirée culturelle avec dîner / Cultural evening with dinner

SAMEDI 19 SEPTEMBRE / SATURDAY, SEPTEMBER 19TH

07:45	Meet the experts : Epilepsie / Epilepsy
09:00	Discussion de Dossiers Cliniques / Clinical case discussion
11:00	MALADIES METABOLIQUES / Metabolic diseases
12:00	SYMPOSIUM GENZYME / GENZYME Symposium
14:00	CONFERENCES / Plenary sessions
16:00	**Communications Orales** / Oral communications
18:00	Remise Prix meilleur Poster et meilleure CO / Award ceremony for best poster and oral communication

JEUDI 17 SEPTEMBRE
THURSDAY SEPTEMBER 17TH

COURS : NEUROLOGIE NÉONATALE
COURSE: NEONATAL NEUROLOGY

Modérateurs/Moderators: Patricia Leroy (Liège), Christian Debauche (Bruxelles/Brussels)

ASPECTS CLINIQUES / Clinical approach

13:30 Epilepsies précoces / Early onset epilepsies
P.Van Bogaert (Bruxelles/Brussels)

14:00 Le nouveau-né hypotonique / The floppy newborn baby
A.Pini (Bologne/Bologna)

14:30 Infarctus cérébral périnatal / Perinatal cerebral ischemic stroke
S. Chabrier (Saint-Etienne)

15:00 Présentation néonatale des maladies métaboliques traitables / Neonatal presentation of treatable metabolic diseases
M-C.Nassogne (Bruxelles/Brussels)

15:30 *Pause et visite des posters / Coffee break and poster session*

EXPLORATIONS COMPLÉMENTAIRES / Complementary investigations

16:00 Intérêt des potentiels évoqués dans la période néonatale / Interest of evoked potentials in the neonatal period
D.Hasaerts (Bruxelles/Brussels)

16:30 EEG néonatal / Neonatal EEG
A.de Villepin (Montpellier)

17:00 Apport de l'échographie cérébrale chez le nouveau-né / Contribution of brain ultrasound exploration in the newborn baby
R.Menten (Bruxelles/Brussels)

17:30 Place de l'IRM cérébrale chez le nouveau-né / Role of the cerebral MRI in the newborn baby
L.Ramenghi (Gênes/Genova)

19:00 CONFERENCE INAUGURALE GILLES LYON / Inauguration conference Gilles Lyon
Aspects non-moteurs des troubles du mouvement chez l'enfant / Non-motor aspects in pediatric movement disorders
E.Fernandez (Barcelone/Barcelona)

20:00 *Cocktail dînatoire / Reception*

VENDREDI 18 SEPTEMBRE
FRIDAY SEPTEMBER 18TH

08:00 Accueil / Welcome

08:20 Mot de bienvenue / Welcome keynote
P.Leroy, Présidente SENP et M-C Nassogne, Présidente du congrès
P.Leroy, SENP President and M-C Nassogne, Conference President

MALADIES NEUROMUSCULAIRES / Neuromuscular diseases
Modérateurs/Moderators: I.Desguerre (Paris), A.Berardinelli (Pavie/Pavia)

08:30 Dystrophies musculaires congénitales : classification et stratégie diagnostique / Congenital muscular dystrophies: classification and diagnostic strategy
F.Rivier (Montpellier)

09:00 Rhabdomyolyse et hyperCKhémie chez l'enfant : approche diagnostique / Rhabdomyolyse and hyperCKemia in children: diagnostic approach
P-Y.Jeannet (Lausanne)

09:30 Syndromes myasthéniques congénitaux : hétérogénéité clinique / Congenital myasthenic syndromes: clinical heterogeneity
M.Mayer (Paris)

10:00 *Pause et visite des posters / Coffee break and poster session*

10:30 COMMUNICATIONS ORALES / Oral communications
Modérateurs/Moderators: C.Korff (Genève/Geneva), J-P.Misson (Liège)

10:30 O1 - Dramatic syncopes with bradycardia in the neonatal period. Have you thought of paroxysmal extreme pain disorder ?
D.Natera-de Benito, *Madrid, Spain*

10:45 O2 - Neurovisual profile in cerebral palsy: from cerebral visual impairment to visuocognitive disorders
J.Galli, *Brescia, Italy*

11:00 O3 - Continuous spikes and waves during slow sleep in perinatal stroke: a multicenter case-control study
A.Garros, *Marseille, France*

11:15 O4 - Incidence and clinical features of paediatric stroke due to lyme disease: data from the paediatric swiss national stroke registry
O.Monteventi, *Geneva, Switzerland*

11:30 O5 - Ischemic stroke in children with heart disease: epidemiology and outcome
E.Barredo Valderrama, *Madrid, Spain*

11:45 O6 - Neuropsychological Disorders Screening Program in new-onset childhood epilepsies
F.Ilski, *Lyon, France*

VENDREDI 18 SEPTEMBRE
FRIDAY SEPTEMBER 18TH

12:00 **SYMPOSIUM PTC / PTC Symposium**

12:00 Introduction : Prise en charge de la maladie de Duchenne en 2015 / Introduction: Management of Duchenne muscular dystrophy in 2015
N.Deconinck Huderf, Bruxelles/Brussels, Belgium

12:30 De la théorie à la pratique : Prise en charge des patients présentant une mutation non-sens dans le gène DMD / From theory to clinical practice: management of patients presenting with nonsense mutation in the DMD gene
I.Desguerre, Paris, France

13:00 *Déjeuner / Lunch*

Modérateurs/Moderators: F.Rivier (Montpellier), F.Christiaens (Bruxelles/Brussels)

14:00 Grilles d'évaluation des enfants atteints de maladies neuromusculaires / Evaluation scales for children with neuromuscular diseases
A.Berardinelli (Pavie/Pavia)

14:30 Diagnostic électrophysiologique des neuropathies périphériques / Electrophysiological diagnosis of peripheral neuropathies
P.Van den Bergh (Bruxelles/Brussels)

15:00 Perspectives thérapeutiques dans l'amyotrophie spinale / Spinal muscular atrophy, therapeutic perspectives
C-I.Ortez (Barcelone/Barcelona)

15:30 *Pause et visite des posters / Coffee break and poster session*

16:00 **COMMUNICATIONS ORALES / Oral communications**
Modérateurs : G.Gobbi (Bologne/Bologna), A.Bernabe-Gelot (Paris)

16:00 O7 - Paroxysmal non-exercise induced movement disorders in glut1 deficiency syndrome
C.Baldassari, *Pavia, Italy*

16:15 O8 - Neuroimaging findings in patients with autism spectrum disorder
M-C.Miranda, *Madrid, Spain*

16:30 O9 - Vitamin D status among children and adolescents with and without anticonvulsant drugs in Southern Switzerland
V.Ramelli, *Bellinzona, Switzerland*

16:45 O10 - Does squatting posture (home-based stretching maneuver) bring 'break through' for spastic cerebral palsy ?
S.Hanaoka, *Chiba, Japan*

VENDREDI 18 SEPTEMBRE
FRIDAY SEPTEMBER 18TH

Modérateurs/Moderators: E.Fazzi (Brescia), A.Bernabe-Gelot (Paris), V.San Antonio (Barcelone/Barcelona)

17:00 Projets de recherche : discussion, méthodologie, proposition de participation / Research projects : discussion, methodology, proposal for participation

1) Cohorte prospective de suivi du parcours de santé des patients polyhandicapés graves (Eval-PLH) / Healthcare pathway follow-up for severely disabled patients: a prospective cohort study
T.Billette de Villemeur (Paris)

2) Comprendre les mécanismes moléculaires et fonctionnels responsables du Syndrome du chromosome 20 en anneau / Understanding the molecular and functional mechanisms sustaining ring chromosome 20 syndrome
P.Canevini, A.Vignoli (Milan/Milano)

3) Ac anormaux après 1e crise chez l'enfant / Abnormal AB after first seizure in children
C.Korff (Genève/Geneva), C.Bien (Bielefeld)

4) Maladies infantiles héréditaires de la substance blanche avec calcifications cérébrales :nouvelles avancées par l'identification de nouveaux phénotypes et leurs bases moléculaires / Infantile inherited white matter diseases with cerebral calcification: new insights from the identification of new phenotypes and their molecular bases
D.Tonduti , N.Nardocci (Milan/Milano)

5) Testing de perception visuelle chez les enfants avec troubles du développement / Visual perception testing in children with neurodevelopmental disorders
S.Gonzales-Monge (Lyon)

18:00 Assemblée générale de la SENP / SENP General Assembly

19:30 *Soirée culturelle avec dîner / Cultural evening with dinner*
Musée du Chocolat / Chocolate Museum
Rendez-vous sur place / Meeting directly onsite

SAMEDI 19 SEPTEMBRE
SATURDAY SEPTEMBER 19TH

07:45 — RENCONTRE AVEC LES EXPERTS : ÉPILEPSIE / MEET THE EXPERTS: Epilepsy
Modérateurs/Moderators: C.Korff (Genève/Geneva), P.A.Veggiotti (Pavie/Pavia), V.San Antonio (Barcelone/Barcelona), A.Arzimanoglou (Lyon), P.Van Bogaert (Bruxelles/Brussels), G.Gobbi (Bologne/Bologna)

Shire

09:00 — Discussion de dossiers cliniques / Clinical case discussion
Modérateurs/Moderators: M-L.Moutard (Paris), B.Echenne (Montpellier)

09:00 — DCC1 - Asymptomatic hyperCKemia: can muscle MR help address the diagnosis?
M.Rossi, *Pavia, Italy*

09:15 — DCC2 - Prise en charge d'un malaise violent lors d'un match de basket. A quoi penser ? / Managing a case of severe fainting during a basketball game. What to make of it?
S.Vaessen, *Liège, Belgium*

09:30 — DCC3 - Dégradation neurologique aigue avec vomissements, état de mal convulsif latéralisé et hémiplégie gauche chez une enfant agée de 3,5 ans / Acute neurological deterioration with vomiting, lateralized seizure and left hemiplegia in a 3.5-year old child
M-C.Nassogne, *Brussels, Belgium*

09:45 — DCC4 - Fatal early onset epileptic encephalopathy and mutation in a previously unreported missense mutation in *BCAP31* in Xq28. What genetic advice should we follow?
J.Lopez Pison, *Zaragoza, Spain*

10:30 — *Pause et visite des posters / Coffee break and poster session*

MALADIES MÉTABOLIQUES / Metabolic diseases

Modérateurs/Moderators: M-C.Nassogne (Brussels), T.Billette de Villemeur (Paris)

11:00 — Convulsions vitamino-sensibles / Vitamin-sensitive seizures
B.Plecko (Zurich)

11:30 — Présentations neurologiques chez l'enfant des maladies mitochondriales / Neurological presentations of mitochondrial diseases in children
E.Della Giustina (Reggio Emilia)

12:00 — SYMPOSIUM GENZYME / Genzyme Symposium
Maladie de Pompe chez l'enfant en 2015 : espoirs et questions / Pompe disease in children in 2015: hope and questions

genzyme
A SANOFI COMPANY

12:00 Présentation, diagnostic différentiel et évolution / Presentation, differential diagnosis and evolution
B.Chabrol, CHU de Marseille, France

12:30 Management et traitement / Management and treatment
F.Labarthe, CHRU de Tours, France

13:00 — *Déjeuner / Lunch*

Modérateurs/Moderators: L.De Meirleir (Bruxelles/Brussels), E.Della Giustina (Reggio Emilia)

14:00 — Expression prénatale des maladies métaboliques / Prenatal presentation of metabolic diseases
T.Billette de Villemeur (Paris)

SAMEDI 19 SEPTEMBRE
SATURDAY SEPTEMBER 19TH

14:30 Métabolisme synaptique : une nouvelle approche des maladies neurométaboliques / Synaptic metabolism: a new approach to neurometabolic diseases
A.Garcia Cazorla (Barcelone/Barcelona)

15:00 Le CDG syndrome en 2015 : clés pour le neuropédiatre / CDG syndrome in 2015: keys for the neuropediatrician
L.de Meirleir (Bruxelles/Brussels)

15:30 *Pause et visite des posters / Coffee break and poster session*

16:00 COMMUNICATIONS ORALES / Oral communications
Modérateurs/Moderators: P.A.Veggiotti (Pavie/Pavia), D.Doummar (Paris)

16:00 O11 - Benign hereditary chorea: the importance of recognizing the phenotype to guide the diagnosis
J.Dominguez-Carral, *Madrid, Spain*

16:15 O12 - Apport de l'ENMG au diagnostic des maladies neuro-métaboliques de l'enfant / ENMG diagnostic relevance for neuro-metabolic diseases in children
I.Ben Youssef Turki, *Tunis, Tunisia*

16:30 O13 - A novel homozygous *TBC1D24* mutation causing multi-focal myoclonus with cerebellar involvement
D.Doummar, *Paris, France*

16:45 O14 - Le syndrome de déficience du transporteur de glucose type 1 / Transporter type 1 deficiency syndrome (Glut1-DS)
I.Naberan-Mardaras, *Pampelune, Spain*

17:00 O15 - Neuro-ophthalmological disorders and their implication in children with Ataxia-Telangiectasia: clinically useful assessment instrument in the management of the disease
A.Molinaro, *Brescia, Italy*

17:15 O16 - Présentations neurologiques chez l'enfant des maladies mitochondriales / Neurological presentations of mitochondrial diseases in children
E.Della Giustina, *Reggio nell'Emilia, Italy*

17:30 O17 - Acidurie arginino-succinique: Faut-il traiter les formes paucisymptomatiques? / Argininosuccinic aciduria: Should we treat clinical types with scarce symptoms?
S.Paquay, *Paris, France*

17:45 O18 - Etude clinique et génétique des 19 patients d'origine serbe/ monténégrine, atteints de la maladie de Lafora / Clinical and genetic study of 19 patients from Serbia/ Montenegro with Lafora progressive myoclonic epilepsy
N.Jovic, *Belgrade, Serbia*

18:00 Remise Prix meilleur Poster et meilleure CO / Award ceremony for best poster and oral communication
Clôture / End of the Conference

POSTERS

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NEURODEVELOPMENTAL OUTCOME OF CHILDREN BORN TO MOTHERS WITH SYSTEMIC AUTOIMMUNE DISEASE: WHICH ROLE FOR ANTIBODIES AGAINST B2GPI?

A.Iodice (1), C.Nalli (2), J.Galli (1), A.Tincani (2), E.Fazzi (1)
(1) Unit of Child and Adolescent Neuropsychiatry, Department of Clinical and Experimental Sciences, Spedali Civili and University of Brescia, Italy
(2) Rheumatology and Clinical Immunology, Department of Clinical and Experimental Sciences, Spedali Civili and University of Brescia, Italy

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EPILEPSY AND ELECTROENCEPHALOGRAPHIC ABNORMALITIES IN PATIENTS WITH ASD

E. Barredo Valderrama (1), C. Miranda Herrero (1), A. Jimenez De Domingo (1), M. Vazquez Lopez (1), P. Castro Castro (1)
(1) Hospital General Universitario Gregorio Marañon, Madrid, España

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TROUBLES ENVAHISSANTS DU DEVELOPPEMENT, CARACTERISTIQUES CLINIQUES, ETIOLOGIQUES ET PRONOSTIQUES SELON LE MODE D'ENTREE DANS LA MALADIE EVALUATION NEUROPEDIATRIQUE DANS UN CENTRE DE DIAGNOSTIC ET D'EVALUATION DE L'AUTISME

F. Beaudonnet (1,2), S. Lacoste (2)
(1) Service de pédiatrie générale, centre hospitalier de Marne la Vallée, Jossigny, France
(2) UNITED, centre de diagnostic et d'évaluation de l'autisme, service de pédopsychiatrie, centre hospitalier de Marne la Vallée, Jossigny, France

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ASTROCYTOME PILOCYTIQUE SUPRA SELLAIRE: A PROPOS D'UN CAS

EL Arbi.A(1), Ben Ncir.A(1), Darmoul.M(1), Hattab.N(1)
(1) Service de neurochirurgie, EPS Fattouma Bourguiba, Monastir, Tunisie

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MP Perriol (1)
Hôpital Jean Bernard, Valenciennes, France

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SYNDROME DE FARH : ÉTUDE DE 5 CAS

Ch. Regaieg, I. Chabchoub, L. Ben Mansour, F. Kamoun, Th. Kamoun, H. Aloulou, M. Hachicha
Service de pédiatrie, CHU Hédi Chaker, Sfax-Tunisie

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I.Bagnasco (1), A.D. Morale (2), D.Di Lisi (3), P. Dassi (1)
1 Child Neuropsychiatry, Ospedale Martini Torino, Italia
2 Pediatrics, Ospedale Martini Torino, Italia
3 Otolaryngology, Ospedale Martini Torino, Italia

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C. Spagnoli, A. Iodice, C. Fusco, G. Bertani, D. Frattini, G.G. Salerno, E. Della Giustina
Service de Neurologie Pédiatrique, Hôpital S. Maria Nuova, Reggio nell'Emilia, Italie

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N. Ben Achour, I. Kraoua, I. Mejri, H. Benrhouma, H. Klaa, A. Rouissi, I. Ben Youssef-Turki
UR12SP24 et Service de Neurologie de l'Enfant et de l'Adolescent Institut National Mongi Ben Hmida de Neurologie. Tunis, Tunisie

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S. Mrabet, N. Ben Achour, I. Kraoua, H. Benrhouma, H. Klaa, A. Rouissi, I. Ben Youssef-Turki
UR12SP24 et Service de Neurologie de l'Enfant et de l'Adolescent – Institut National Mongi Ben Hmida de Neurologie. Tunis. Tunisie

POSTERS

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N. Ben Achour, I. Kraoua, H. Benrhouma, H. Klaa, A. Rouissi, I. Ben Youssef-Turki
UR12SP24 et Service de Neurologie de l'Enfant et de l'Adolescent, Institut National Mongi Ben Hmida de Neurologie. Tunis. Tunisie

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S. Garcia-Tarodo (1), L. Jardinier (1), P. Lalive (2), C. Korff (1)
(1) Pediatric Neurology, Department of Child and Adolescent, Geneva University Hospitals, Geneva, Switzerland, (2) Unit of Neuroimmunology and Multiple Sclerosis, Division of Neurology, Geneva University Hospitals, Geneva, Switzerland

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C. Freihuber(1), M.T. Vanier(2, 10), A. Brassier(3, 10), P. Broué (4), B. Chabrol (5, 10), D. Eyer (6, 10), N. Guffon (2, 10), F. Labarthe (7, 10), P. Latour(2, 10), T. Levade (4, 10), S. Pichard (8, 10), S. Roche (4, 10), C. Sevin (9, 10), V. Valayannopoulos (3, 10), B. Héron (1, 10)
(1) CHU Trousseau, Paris, France, (2) HCL, Lyon-Bron, France, (3) CHU Necker –Enfants Malades, Paris, France, (4) CHU Toulouse, France, (5) CHU La Timone, Marseille, France, (6) CHU Strasbourg, France, (7) CHU Clocheville, Tours, France, (8) CHU Robert Debré, Paris, France, (9) CHU Kremlin Bicêtre, France, (10) Comité d'Evaluation du Traitement des NeuroLipidoses, France

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L.Sfaihi (1), S.Alibi (1), H.Fourati (2), H.Zouari (3), T.Kamoun (1), K.Masmoudi (3), Z. Mnif (2), M.Hachicha (1)
(1) Department of Pediatrics University Hospital Hedi Chaker Sfax Tunisia
(2) Department of radiology University Hospital Hedi Chaker Sfax Tunisia
(3) Department of functional explorations, Habib Bourguiba Hospital Sfax, Tunisia

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L. Sfaihi, Y.belfitouri, C.Regaieg, I.Maaloul, F.Kamoun, H.Aloulou, T.KAMOUN, M.HACHICHA
Department of Pediatrics, University Hospital Hedi Chaker Sfax Tunisia

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D. Boumendil[1], MA. Negadi[1], N. Kharoubi[2], H. Bouguetof[1], K El Halimi[1], Z. Mentouri[1]
(1) Réanimation pédiatrique CHU Oran. Faculté de médecine d'Oran, Algérie. Laboratoire d'accidentologie.
(2) Laboratoire de biostatistique faculté de médecine d'Oran, Algérie

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Service de Neurologie Pédiatrique, Hopital S. Maria Nuova, Reggio nell'Emilia, Italie, ..avec la contribution de RING 14 International Association...

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MC. Nouguès (1,2), V. Buret (1,3), S. Valence (1,2), N. Teraa (1,3), D.Rodriguez (1,2,3)
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VISUOSPATIAL FUNCTIONS AND PREMATURITY

M C. Miranda (1), E. Barredo (1), A. Jiménez (1), M. Vázquez (1), P. Castro (1), SI. Pascual (2)
(1) H.G.U Gregorio Marañón, Madrid, Spain, (2) H.G.U La Paz, Madrid, Spain

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INSCRIPTION AU COURS *Course registration fee*	60 €
INSCRIPTION DÎNER ET EXCURSION *Site visit and dinner registration fee*	65 €*

Vendredi 18 septembre
au Restaurant Aux Armes de Bruxelles
(13, rue des Bouchers - Bruxelles)

PROGRAMME :

- A partir de 19:30 :
Visite culturelle au Musée du Chocolat.
Rendez-vous sur place
au 9/11 rue de la Tête d'Or - 1000 Bruxelles.

- A partir de 21:00 :
Dîner au Restaurant Aux Armes de Bruxelles
Pas de retour aux hôtels organisés par le congrès, possibilité de rentrer en métro, tram ou taxi
(Taxis Verts 02 349 49 49).

Friday, September 18
at the Restaurant Aux Armes de Bruxelles
(13, rue des Bouchers - Bruxelles)

PROGRAM :

- Starting at 7.30 pm:
Cultural visit of the Chocolate Museum.
Meeting directly onsite at 9/11 rue de la Tête d'Or - 1000 Brussels.

- Starting at 9 pm:
Dinner at the restaurant
"Aux Armes de Bruxelles ».
No returns to the hotels organized by the conference, possibility of returning in Metro, Tramway or Taxi (Taxis Verts 02 349 49 49)

ACCES
CONGRESS VENUE

ACCES BRUXELLES

- **BRUSSELS AIRPORT**

Brussels Airport est situé à Zaventem à 12 kilomètres en voiture du centre ville, dans la périphérie nord de Bruxelles.

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ACCES LIEU DU CONGRES

Le congrès aura lieu à la MAISON DES ASSOCIATIONS INTERNATIONALES de Bruxelles.

Adresse : La M.A.I
40 rue Washington - 1050 Bruxelles

- **En taxi**

A partir des gares ferroviaires, comptez 12/15 min en taxi.

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A partir de la GARE DU MIDI :
TramN°81 > arrêt Bailli.
Environ 20 minutes de trajet.

A partir de la GARE CENTRALE :
Itinéraire 1 : Bus N°38 direct de Gare Centrale > arrêt Vleurgat.
Environ 27 minutes de trajet, dont 500m à pied entre Vleurgat et la MAI.

Itinéraire 2 : 500m de marche. Tram N°93 direct de Parc > arrêt Bailli.
Environ 21 minutes de trajet, dont 500m à pied en côte entre Gare Centrale et Parc.

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500m de marche. Métro N°2/6 à Rogier > arrêt Louise (soit 6 arrêts). Changement à Louise. Tram N°93/94 > arrêt Bailli.
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A partir de l'AEROPORT :
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The ride between the airport and the City Center of Brussels will be approximately 45€. The official taxi cabs can be identified by the blue and yellow license, avoid unlicensed cabs.

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Itinerary 1: Bus N°38 direct from Gare Centrale > stop at Vleurgat.
Approximately a 27-min ride, including 500m walking between Vleurgat and MAI.

Itinerary 2: 500m walking distance. Tram N°93 from Parc > stop at Bailli.
Approximately a 21-min ride, 500m steep walking between Gare Centrale and Parc.

From the GARE DU NORD:
500m walking distance. Metro N°2/6 at Rogier > stop at Louise (i.e. 6 stops). Change at Louise. Tram N°93/94 > stop at Bailli.
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ACCUEIL DU CONGRÈS

Horaires d'ouverture :
Jeudi 17 septembre de 12h30 à 19h30
Vendredi 18 Septembre de 07h30 à 19h00
Samedi 19 Septembre de 07h00 à 18h30

CONGRESS REGISTRATION DESK

Opening hours :
Thursday, September 17th: 12:30 to 7:30
Friday, September 18th: 7:30 to 19:00
Saturday, September 19th: 7:00 to 18:30

RESTAURATION / CATERING

Apéritif de bienvenue pour les inscrits au congrès SENP (exceptés les inscrits au cours) le jeudi 17 septembre à 20h00. Cocktail dinatoire à la MAI avec le groupe de musique Geminides.
Welcome cocktail reception for SENP attendees (except those attending the SENP classes) Thursday, September 17th at 20:00. The reception will take place at the MAI with music performed by Geminides

Les déjeuners se dérouleront dans une salle attenante à l'espace d'exposition. Les desserts et les pauses seront servis sur l'espace d'exposition.
Lunches will take place in the exhibit hall. Desserts and coffee breaks will take place in the exhibit hall.

Le dîner du congrès aura lieu le Vendredi 18 Septembre au Restaurant Aux Armes de Bruxelles.
The congress dinner will take place on Friday, September 18th at the «Restaurant Aux Armes de Bruxelles».
Inscriptions sur */ Registration on* : www.senp-neuropediatrie.eu

POSTERS

Dimensions : hauteur 1.10 m / largeur 0.90 m.
Le matériel de fixation du poster sera remis à l'accueil.
Dimensions : height 1.10m / width : 0.90m
Fixing supplies will be handed out to you onsite at the congress secretariat.

Affichage : Jeudi 17 Septembre avant 15h00
Retrait : Samedi 19 Septembre au plus tard à 18h30 (aucun poster ne sera gardé après)
Posters set-up : Thursday, September 17th before 15:00
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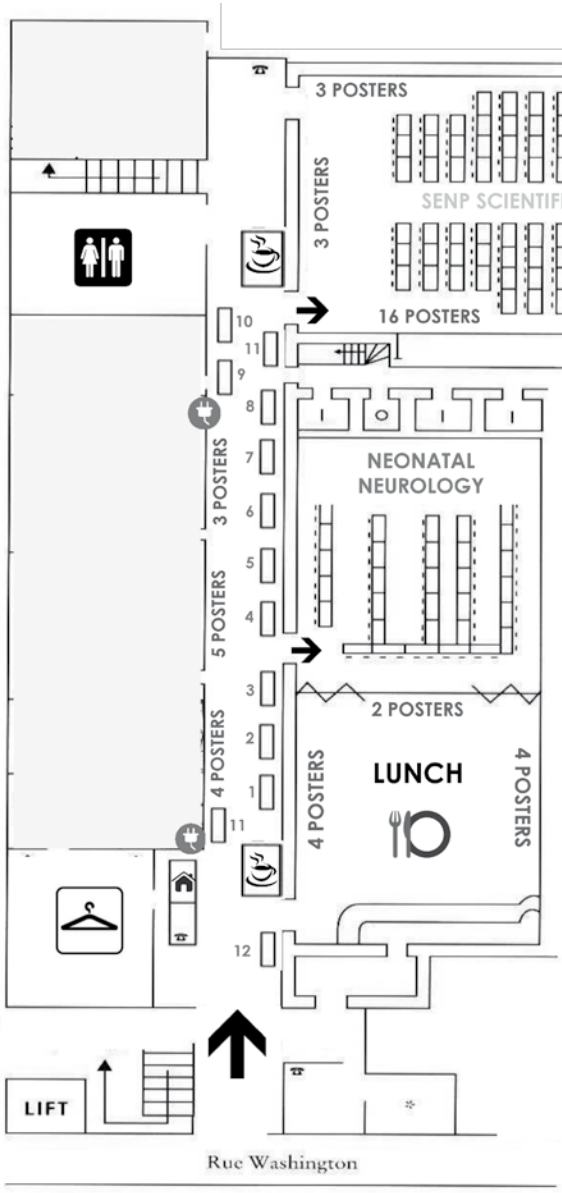

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NOTES

on clinical judgment. The recommended dose of 50 mg/kg/day is based on the available clinical study findings and was the only dose of Diacomit evaluated in the pivotal studies. There are no clinical study data to support the clinical safety of stiripentol administered at daily doses greater than 50 mg/kg/day. There are no clinical study data to support the use of stiripentol as monotherapy in Dravet's syndrome. *Children aged less than 3 years:* The pivotal clinical evaluation of Diacomit was in children of 3 years of age and over with SMEI. The clinical decision for use of Diacomit in children with SMEI less than 3 years of age needs to be made on an individual patient basis taking into consideration the potential clinical benefits and risks. In this younger group of patients, adjunctive therapy with Diacomit should only be started when the diagnosis of SMEI has been clinically confirmed (see section 5.1). Data are limited about the use of Diacomit under 12 months of age. For these children the use of stiripentol will be done under the close supervision of the doctor. Patients aged ≥ 18 years of age: Long-term data has not been collected in a sufficient number of adults to confirm maintenance of effect in this population. Treatment should be continued for as long as efficacy is observed. Dose adjustments of other antiepileptics used in combination with Diacomit : – Clobazam: In the pivotal studies, when the use of Diacomit was initiated, the daily dose of clobazam was 0.5 mg/kg/day usually administered in divided doses, twice daily. In the event of clinical signs of side effects or overdosage of clobazam, this daily dose was reduced by 25% every week. Approximately two to three fold increases in clobazam and five fold increases in norclobazam plasma levels respectively have been reported with co-administration of Diacomit in children with Dravet's syndrome. – Valproate: The potential for metabolic interaction between Diacomit and valproate is considered modest, no modification of valproate dosage should be needed when Diacomit is added. In the pivotal studies, the daily dose of valproate was reduced by around 30% every week. Abnormal Laboratory Findings : In the event of an abnormal blood count or liver function test finding, the clinical decision for continuing use or adjusting the dose of Diacomit in conjunction with adjusting the doses of clobazam and valproate needs to be made on an individual patient basis. Effect of formulation : The sachet formulation has a slightly higher Cmax than the capsules and thus the formulations are not bioequivalent. It is recommended that if a switch of formulations is required this is done under clinical supervision, in case of problems with tolerability. Renal and hepatic impairment : Diacomit is not recommended for use in patients with impaired hepatic and/or renal function. Method of administration - Precautions to be taken before handling or administering the medicinal product: The capsule should be swallowed whole with a glass of water during a meal. The powder should be mixed in a glass of water and should be taken immediately after mixing during a meal. Diacomit must always be taken with food as it degrades rapidly in an acidic environment. Diacomit should not be taken with milk or dairy products, carbonated drinks, fruit juice or food and drinks that contain caffeine or theophylline. **Contraindications**: Hypersensitivity to the active substance or to any of the excipients. Past history of psychoses in the form of episodes of delirium. **Special warnings and precautions for use**: Carbamazepine, phenytoin and phenobarbital should not be used in conjunction with Diacomit in the management of Dravet's syndrome. The daily dosage of clobazam and/or valproate should be reduced according to the onset of side effects whilst on Diacomit therapy. Growth rate of children : given the frequency of gastrointestinal adverse reactions to treatment with Diacomit and valproate, the growth rate of children under this combination of treatment should be carefully monitored. Blood counts: Neutropenia may be associated with the administration of stiripentol, clobazam and valproate. Blood counts should be assessed prior to starting treatment with stiripentol. Unless otherwise clinically indicated, blood counts should be checked every 6 months. Renal and hepatic impairment: Diacomit is not recommended for use in patients with impaired hepatic and/or renal function. Substances interfering with CYP enzymes: Stiripentol is an inhibitor of the enzymes CYP2C19, CYP3A4 and CYP2D6 and may markedly increase the plasma concentrations of drugs metabolised by these enzymes and increase the risk of adverse effects. In vitro studies suggested that stiripentol phase 1 metabolism is catalyzed by CYP1A2, CYP2C19 and CYP3A4 and possibly other enzymes. Caution is advised when combining stiripentol with other drugs that inhibit or induce one or more of these enzymes. The pivotal clinical studies did not include children below 3 years old. As a consequence, it is recommended that children between 6 months and 3 years of age are carefully monitored whilst on stiripentol therapy Potential medicinal product interactions affecting stiripentol: The influence of other antiepileptic medicinal products on stiripentol pharmacokinetics is not well established. The impact of macrolides and azole antifungal agents on stiripentol metabolism, that are known to be inhibitors of CYP3A4 and substrates of the same enzyme, is not known. Likewise, the effect of stiripentol on their metabolism is not known. In vitro studies suggested that stiripentol phase 1 metabolism is catalyzed by CYP1A2, CYP2C19 and CYP3A4 and possibly other enzymes. Caution is advised when combining stiripentol with other drugs that inhibit or induce one or more of these enzymes. Effect of stiripentol on cytochrome P450 enzymes: Many of these interactions have been partially confirmed by in vitro studies and in clinical trials. The increase in steady state levels with the combined use of Diacomit, valproate, and clobazam is similar in adults and children, though inter-individual variability is marked. At therapeutic concentrations, stiripentol significantly inhibits several CYP450 isoenzymes: for example, CYP2C19, CYP2D6 and CYP3A4. As a result, pharmacokinetic interactions of metabolic origin with other medicines may be expected: citalopram, omeprazole, HIV protease inhibitors, astemizole, chlorpheniramine, calcium channel blockers, statins, oral contraceptives, codeine. A dose adjustment may be necessary. Interactions with theophylline and caffeine cannot be excluded. Use in combination with stiripentol is not recommended. As stiripentol inhibited CYP2D6 in vitro at concentrations that are achieved clinically in plasma, drugs that are metabolized by this isoenzyme like: propranolol, carvedilol, timolol, fluoxetine, paroxetine, sertraline, imipramine, clomipramine, haloperidol, codeine, dextromethorphan, tramadol may be subject to metabolic interactions with stiripentol. **Potential for stiripentol to interact with other medicinal products**: In the absence of available clinical data, caution should be taken with the following clinically relevant interactions with stiripentol: **-** Undesirable combinations : Rye ergot alkaloids, cisapride, halofantrine, pimozide, quinidine, bepridil, immunosuppressants and statins. - Combinations requiring precautions : Midazolam, triazolam, alprazolam, theophylline, caffeine, chlorpromazine. - Effects on other AEDs : pharmacokinetic interactions with phenobarbital, primidone, phenytoin, carbamazepine, clobazam, valproate, diazepam, ethosuximide, and tiagabine → potential risk of overdose. Topiramate: it is considered that potential competition of inhibition on CYP2C19 should not occur • Levetiracetam: no pharmacokinetic metabolic drug interaction between stiripentol and levetiracetam is anticipated. **Pregnancy** Risk related to epilepsy and antiepileptic medicinal products in general: It has been shown that in the offspring of women with epilepsy, the prevalence of malformations is two to three times greater than the rate of approximately 3% in the general population. Although other factors, e.g. the epilepsy, can contribute, available evidence suggests that this increase, to a large extent, is caused by the treatment. In the treated population, an increase in malformations has been noted with polytherapy. However, effective anti-epileptic therapy should not be interrupted during pregnancy, since the aggravation of the illness may be detrimental to both the mother and the foetus. Risk related to stiripentol: No data on exposed pregnancies are available. Animal studies do not indicate direct or indirect harmful effects with respect to pregnancy, foetal development, parturition or postnatal development at non-maternotoxic doses. In view of the indication, administration of stiripentol during pregnancy and in women of childbearing potential would not be expected. The clinical decision for use of stiripentol in pregnancy needs to be made on an individual patient basis taking into consideration the potential clinical benefits and risks. Caution should be exercised when prescribing to pregnant women and use of efficient methods of contraception is advisable. During pregnancy: Effective anticonvulsant treatment with stiripentol must not be stopped during pregnancy as worsening of the disease is potentially harmful to both mother and foetus. **Breastfeeding**: In the absence of human studies on excretion in breast milk, and given that stiripentol passes freely from plasma into milk in the goat, breastfeeding is not recommended during treatment. In case stiripentol therapy is continued during breastfeeding, the breastfed infant should be carefully observed for potential adverse effects. **Fertility**: No impact on fertility was detected in animal studies. No clinical data are available, potential risk for human is unknown. **Undesirable effect**: The most common side effects with Diacomit (seen in more than 1 in 10 patients) are anorexia, weight loss, insomnia, drowsiness, ataxia, hypotonia and dystonia. Adverse reactions encountered most often are as follows: very common (≥1/10), common (≥1/100, < 1/10), uncommon (≥1/1,000, < 1/100), rare (≥1/10,000, < 1/1,000), very rare (< 1/10,000, including isolated cases), frequency not known (cannot be estimated from the available data). Within each frequency grouping, undesirable effects are presented in order of decreasing severity. System/organ classes • Blood and lymphatic system disorders = common: Neutropenia. Persistent severe neutropenia usually resolves spontaneously when Diacomit is stopped. Rare: thrombocytopenia (thrombocytopenia data are derived from both clinical trials and post-marketing experience) • Metabolism and nutrition disorders = very common: Anorexia, loss of appetite, weight loss (especially when combined with sodium valproate). • Psychiatric Disorders = very common: Insomnia; Common: Aggressiveness, irritability, behaviour disorders, opposing behaviour, hyperexcitability, sleep disorders. • Nervous system disorders = very common: Drowsiness, ataxia, hypotonia, dystonia; Common: Hyperkinesias. • Eye disorders = Uncommon: Diplopia (when used in combination with carbamazepine). • Gastrointestinal disorders = Common: Nausea, vomiting. • Skin and subcutaneous tissue disorders = Uncommon: Photosensitivity, rash, cutaneous allergy, urticaria. • General disorders = Uncommon: Fatigue. • Investigations = Common: Raised γGT (notably when combined with carbamazepine and valproate). Rare: liver function test abnormal. Many of the above adverse reactions are often due to an increase in plasma levels of other anticonvulsant medicinal products and may regress when the dose of these medicinal products is reduced. Description of selected adverse reactions: Many of the above adverse reactions are often due to an increase in plasma levels of other anticonvulsant medicinal products and may regress when the dose of these medicinal products is reduced. Reporting of suspected adverse reactions : Reporting suspected adverse reactions after authorisation of the medicinal product is important. It allows continued monitoring of the benefit/risk balance of the medicinal product. Healthcare professionals are asked to report any suspected adverse reactions via the national reporting system Overdose**:** Supportive treatment (symptomatic measures in intensive care units). **Pharmacological properties:** Pharmacodynamic properties: Other Antiepileptics, ATC code: N03AX17. **- Marketing Authorisation Numbers:** Diacomit® 250mg, 60 capsules: EU/1/06/367/002 - Diacomit® 500mg 60 capsules: EU/1/06/367/005 **-** Diacomit® 250mg powder for oral suspension, 60 sachets: EU/1/06/367/008 - Diacomit® 500mg powder for oral suspension, 60 sachets: EU/1/06/367/011. **Date of first authorisation/revision of the text**: 04 January 2007 / Rev. June 2014. For further information, contact the Marketing Authorisation Holder**: Biocodex**, 7 Avenue Gallieni, 94250 Gentilly, France – Tel.: + 33 1 41 24 30 00 – e-mail: webar@biocodex.fr.

DRAVET SYNDROME

DIACOMIT®
(stiripentol)
Committed to controlling seizures

BIOCODEX

Name of the medicinal product: DIACOMIT® 250mg hard capsules - DIACOMIT® 500mg hard capsules - DIACOMIT® 250mg powder for oral suspension in sachets - DIACOMIT® 500mg powder for oral suspension in sachets. **Qualitative and quantitative composition and pharmaceutical form**: DIACOMIT® 250mg caps.: 250mg of stiripentol/caps. and 0.16mg sodium. - DIACOMIT® 500mg caps.: 500mg/caps. of stiripentol and 0.32mg sodium. DIACOMIT® 250mg pder f. oral susp./sachet.: 250mg/sac. of stiripentol and 0.11mg sodium. - DIACOMIT® 500mg pder f. oral susp./sachet.: 500mg/sac. of stiripentol and 0.22mg sodium. **Therapeutic indications**: Diacomit is indicated for use in conjunction with clobazam and valproate as adjunctive therapy of refractory generalized tonic-clonic seizures in patients with severe myoclonic epilepsy in infancy (SMEI, Dravet's syndrome) whose seizures are not adequately controlled with clobazam and valproate. **Posology and method of administration**: Diacomit should only be administered under the supervision of a paediatrician / paediatric neurologist experienced in the diagnosis and management of epilepsy in infants and children. Paediatric population : The dose of Diacomit is calculated on a mg/kg/day basis in 2 or 3 divided doses. The initiation of adjunctive therapy with Diacomit should be undertaken gradually using upwards dose escalation to reach the recommended dose of 50 mg/kg/day administered in conjunction with clobazam and valproate. Stiripentol dosage escalation should be gradual, starting with 20mg/kg/day for 1 week, then 30mg/kg/day for 1 week. Further dosage escalation is age dependent: - children less than 6 years should receive an additional 20 mg/kg/day in the third week, thus achieving the recommended dose of 50 mg/kg/day in three weeks; - children from 6 to less than 12 years should receive an additional 10 mg/kg/day each week, thus achieving the recommended dose of 50 mg/kg/day in four weeks; - children and adolescents 12 years and older should receive an additional 5 mg/kg/day each week until the optimum dose is reached based