



**BSPN CONGRESS - Liège, February 25<sup>th</sup> 2022**

**NEUROMUSCULAR DISEASES : PROGRAM**

09:00 - 09:30

**REGISTRATION**

09:25 - 09:30

**WELCOME:** Laurent SERVAIS, Patricia LEROY

**SESSION 1**

Chairs : Laurent SERVAIS, Gunnar BUYSE

09:30 - 10:00

*Four years of NBS for SMA in French-speaking Belgium. What have we learned (that we did not know before)?*

Aurore DARON, Liège

10:00 - 10:30

*What is going on in Duchenne muscular dystrophy?*

Liesbeth DE WAELE, UZ Leuven

10:30 - 11:00

*Digenic heredity*

Volker STRAUB, Newcastle

**11:00 - 11:30**

**COFFEE BREAK**

**SESSION 2**

Chairs : Nicolas DECONINCK, Helene VERHELST

11:30 - 12:00

*Exome in NMD. Insight and limitation.*

Sandra COPPENS, ULB

12:00 - 13:00

Free Communications:

Muscular dystrophy as an important feature of CTBP1-related syndrome.  
Eliane EL HOWAYEK, HUDERF

A severe form of familial desminopathy due to homozygous nonsense variations in DES in two siblings.

Laura CLAES, UZ Antwerpen

HHV-6 encephalitis: not as rare as we think?

Nele WILLEMYNS, UZ Leuven

Hypertonia in a neonate: a startling topic.

Berthold AMAN, UZ Brussel

**13:00 - 14:00**

**LUNCH**



### **SESSION 3**

Chairs : Marie-Cécile NASSOGNE, Liesbeth DE WAELE

14:00 - 14:30

*AAV gene based therapy. Is it the past or the future?*

Nicolas DECONINCK, HUDERF (future) - Laurent SERVAIS, Liège (past)

14:30 - 15:00

*Do we still need muscle biopsy?*

Kristl CLAEYS, KUL

15:00 - 16:00

**Ethical session:** Crowdfunding to pay expensive drugs when not reimbursed.

- *Treating a crowd funded patient in Antwerp and Liege.*  
Diane BEYSEN, Antwerp, Laura VANDEN BRANDE, Liège.
- *Ethical implications of crowd funding.*  
Dominic WILKINSON, Oxford

16:00

Grant for the best oral communication and closing thanks.