The Nopho-European Study on Cerebellar Mutism Syndrome (CMS)

Wibroe, Morten; Avula, Shivaram; Cappelen, Johan; Castor, Charlotte; Clausen, Niels; Devenney, Irene; Fellows, Greg; Grillner, Pernilla; Gupta, Ramneek; Gustavsson, Bengt; Heyman, Mats; Holm, Stefan; Karpinnen, Atte; Kiudeliene, Rosita; Klausen, Camilla; Lahteenmaki, Paivi; Lönnqvist, Tuula; Lowis, Stephen; Mallucci, Conor; Mathiasen, Rene; Mattson, Mattias; Nilsson, Pelle; Nordfors, Kristiina; Nyman, Per; Nysom, Karsten; Persson, Karin; Pesola, Jouni; Pizer, Barry; Rask, Olof; Sabel, Magnus; Schmiegelow, Kjeld; Sehested, Astrid; Tonning-Olsson, Ingrid; Torsvik, Ingrid Kristin; van Baarsen, Kirsten; Walker, David; Westerholm-Ormio, Mia; Zetterqvist, Barbara; Juhler, Marianne

Published in:
Neuro-Oncology

Link to article, DOI:
10.1093/neuonc/now066.5

Publication date:
2016

Document Version
Publisher’s PDF, also known as Version of record

Link back to DTU Orbit

Citation (APA):

DTU Library
Technical Information Center of Denmark

General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.
CMS-06. THE NOPHO-EUROPEAN STUDY ON CEREBELLAR MUTISM SYNDROME (CMS)

Morten Wibroe1, Shivaram Avula1, Johan Cappelen1, Charlotte Castor2, Niels Clausen3, Irene Devenney4, Greg Fellows21, Pernilla Grillner7, Ramneek Gupta8, Bengt Gustavsson5, Mats Heyman7, Stefan Holm7, Atte Karppinen9, Rosita Kiudeliene10, Camilla Klausen1, Paivi Lähteenmäki11, Tuula Lönnqvist9, Stephen Lowis21, Conor Mallucci2, René Mathiasen1, Mattias Mattson12, Pelle Nilsson13, Kristina Nordfors14, Per Nyman15, Karsten Nysom19, Karin Persson15, Jouni Pesola20, Barry Pizer2, Olof Rask4, Magnus Salvé16, Kjeld Schmiegelow1, Astrid Sehested1, Ingrid Tonning-Olsson4, Ingrid Kristin Torsvik17, Kirsten van Baarsen18, David Walker19, Mia Westerholm-Ormio8, Barbara Zetterqvist7, and Marianne Juhler1;

University Hospital Rigshospitalet, Copenhagen, Denmark;2 Alder Hey Children's Hospital, Liverpool, UK; 3 St Olavs University Hospital, Trondheim, Norway; 4 University Hospital, Rikshospitalet, Copenhagen, Denmark; 5 A˚kersted, Aalborg, Denmark; 6 Linköping University Hospital, Linköping, Sweden; 7 Karolinska University Hospital, Stockholm, Sweden; 8 Technical University of Denmark, Copenhagen, Denmark; 9 Helsinki University Hospital, Helsinki, Finland; 10 Hospital of Lithuanian University of Health Sciences Kauno Klinikos, Kaunas, Lithuania; 11 Tampere University Hospital, Tampere, Finland; 12 University Hospital of Umeå, Umeå, Sweden; 13 Uppsala University Hospital, Uppsala, Sweden; 14 Tampere University Hospital, Tampere, Finland; 15 BarnReHab Skåne, Lund, Sweden; 16 Sahlgrenska University Hospital, Göteborg, Sweden; 17 Haukeland University Hospital, Bergen, Norway; 18 Radboud University Medical Centre, Nijmegen, The Netherlands; 19 Children Brain Tumour Research Centre, Nottingham, UK; 20 Kuopio University Hospital, Kuopio, Finland; 21 Bristol Royal Children's Hospital, Bristol, UK

BACKGROUND: The cerebellar mutism syndrome (CMS) is one of the most disabling late effects after neurosurgery for a posterior fossa tumour in childhood. The reported incidences vary substantially in previous studies. AIMS: Pathophysiology is unknown, but damage to cerebello-thalamo-cerebral circuits is likely. The study focuses on the risk factors for development and severity of CMS including surgery (approaches, techniques and tissue and vascular damage, re-operation) and host genome variants. METHODS: Multicentre study developed as a NOPHO collaborative study coordinated from Righospitalet, Copenhagen with online data registration and database management at Karolinska, Stockholm and quarterly online participant meetings. Registration includes clinical data and speech samples collected preoperatively and at four defined postoperative points for the subsequent 12 months. Therapy, including neurosurgery, is by local standards. A blood sample for genetic analysis is collected from all patients. Imaging is collected and reviewed centrally. RESULTS: The study aims to recruit 550 children. It opened in five Nordic and Baltic countries during 2014/2015; in the Netherlands in February 2016 and will open in the UK during 2016. Two German centres will join in 2017. The target accrual of 550 patients will be reached by the end of 2018. As of February 2016, 67 patients have been included from 12 centres. Mutism has occurred in 7 cases. CONCLUSION: The study will be the largest prospective international study on CMS to date, and the first one to 1) systematically register surgery, use of steroids, standardized speech samples and 2) to investigate the influence of host genome.