Hip luxation in cerebral palsy – a European survey

Himmelmann K, Pålhlman M, Andersen G, Vik T, Horridge K, Andrada MG, Arnaud C, De la Cruz J.
On behalf of the Surveillance of Cerebral palsy in Europe (SCPE-NET)

Background and aim
In cerebral palsy (CP) secondary complications, such as hip luxation, affect the quality of life for children and families. Without hip screening combined with active intervention in the case of hip dislocation, 10-20% will have a hip luxation. The aim of this study was
• To survey the current standards of follow-up of hip displacement and prevention of hip luxation across Europe.
• To document health economic variation in the participating countries, and to study the association to the presence of follow-up programmes or guidelines for hip management

Methods
SCPE partners and clinical networks contributed with hip data on children with spastic and dyskinetic CP, 8-10 years old, at Gross Motor Function Classification System (GMFCS) levels III-V.
Surveys were sent to countries, centres and clinical networks across Europe, regarding systematic registration of hip status, standard definition and diagnosis of hip luxation and guidelines for management or prevention of hip luxation in children with CP. Gross Domestic Product (GDP), percentage of GDP spent on health (%GDP) and Gini coefficient (inequality of income) for the participating countries, were documented.

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Results on country/register level
15 of 31 responders across Europe registered hip status in children with CP, and 20 reported guidelines for hip management used for 1-23 years. Several guidelines were reported to be underway.

Conclusion
• Although definitions of hip luxation vary, areas with hip follow-up programme for hip management appear to have a lower occurrence of hip luxation.
• The presence of a follow-up programme is not associated with health economic variables.
• The number of countries with follow-up programmes is increasing.
• Such guidelines constitute a foundation for decisions regarding management of the secondary complications in CP.

Results on patient level
Population-based data were provided by Norway, England, Portugal and Sweden. CP-Netz reported data from 12 German centers. The occurrence of hip luxation differed between centres (p<0.01). However, definitions for hip luxation varied between migration index >65% and 100%. Children who had undergone surgery were at GMFCS level III in 17%, IV in 29% and V in 54%, and differed in CP type between centres (p<0.01), but the majority (69%) had bilateral spastic CP.
Intrathecal baclofen treatment in children with cerebral palsy across Europe

Himmelmann K, Pålman M, Andersen G, Vik T, Horridge K, Andrade MG, Neubauer D, Arnaud C, De la Cruz J.
On behalf of the Surveillance of Cerebral palsy in Europe (SCPE-NET)

Background and aim
In cerebral palsy (CP) secondary complications due to spasticity are common, affecting quality of life for children and their family/carers. Intrathecal baclofen (ITB) has been shown to improve the management of spasticity and pain. The aim of this study was

• To describe variations in ITB treatment across Europe for children with CP.
• To document health economic variation in the participating countries, and study the association to the access to ITB.

Methods and subjects
Surveys were sent to SCPE partners and clinical networks, exploring the possibilities of data collection regarding children with CP and ITB, and to countries across Europe exploring the availability of ITB on national/regional/local level. Additional information was accessed through Medtronic, manufacturer of medical pumps. Results were related to Gross Domestic Product, GDP, % of GDP spent on health. Children born 1990-2005, with spastic and dyskinetic CP, at all GMFCS levels were included.

Results on patient level
In register data provided by Sweden, Norway, Northern England, Portugal (Lisbon area) and Slovenia, 75 (3.4%) of 2217 had ITB, ranging from 0.4% to 4.7% by centre. Of all treated children known, 155 (95%) of 163 were non-walkers, 108 were boys and 55 girls. Gender difference was significant among Swedish children, where 6.3% of boys and 2.5% of girls with CP had ITB (p=0.002). Age at implant differed between centres (p<0.01), Norway had the youngest implant age (<5 y), while mostly older children received ITB in the other centres, 55% being 10 years or older. The Netherlands and Belgium reported a mean age at implant of 12 years and 7.8 years, respectively, in mostly children with GMFCS V, and occasional walkers.

Conclusions
• Access to ITB for children with CP varies by health economic factors, but are probably also depending on local clinician’s choices and experience.
• The difference in access to ITB treatment illustrates the inequalities of care for children with CP in Europe.

Results on country/centre level
27 of 32 responders from 22 countries across Europe reported availability of ITB for children with CP. The access to ITB for children with CP correlated to GDP per capita (p<0.01) and % GDP spent on health (p<0.01). The distribution ranged from single centres to several centres per country. Duration of ITB access ranged from a few years up to 20 years.

<table>
<thead>
<tr>
<th>Area</th>
<th>Sweden (west/south)</th>
<th>Norway</th>
<th>Portugal (Lisbon area)</th>
<th>Northern England</th>
<th>Slovenia</th>
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</thead>
<tbody>
<tr>
<td>Boys ITB</td>
<td>43</td>
<td>10</td>
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<td>1</td>
<td>1</td>
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<tr>
<td>Girls ITB</td>
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<td>0</td>
<td>0</td>
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<tr>
<td>Total</td>
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<td>13</td>
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<td>1</td>
<td>1</td>
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<tr>
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<td>0</td>
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<td>0</td>
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<tr>
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<td>1</td>
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<tr>
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<td>1</td>
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</table>

ITB treatment in five European countries.