COST Action BM1004
Enhancing the Scientific Study of Early Autism (ESSEA)

WG1: At-risk groups
Initial Mapping Exercise Summary

Key points
- Investigation of high-risk groups is clearly an emerging field in Europe. Despite the relatively small number of studies, current projects range from large-scale collaborative initiatives to small pilots, and planned projects.
- Current populations under investigations are infant siblings of children with autism, preterm infants, and those with neonatal abstinence syndrome and fetal alcohol syndrome.
- Areas of expertise of WG members are diverse and include genetics, neuroscience, infancy, and clinical research.
- Contributing members suggested that the WG can enhance research and practice through a wide range of discussion topics overlapping with other WGs. The mapping exercise did not yield very clear priorities within those topics. Hence, further consensus building is needed to formulate specific priorities.
- Given the group’s diversity, there is limited overlap in regular conference attendance. Phone/virtual meetings are the most appropriate medium for communication.

Chair / Co-Chair
Sven Bölte (Sweden)/Chantal Kemner (Netherlands) (previously Mayada Elsabbagh (UK))

Members
- Belgium: Herbert Roeyers, Petra Warreyn
- Czech Republic: Michal Hrdlicka
- Germany: Luise Poustka
- Israel: Nurit Yirmiya, David Mankuta
- Italy: Teresa Farroni
- Ireland: Louise Gallagher
- Macedonia: Vladimir Trajkovski
- Portugal: Astrid Vicente
- Romania: Magdalena Budisteanu
- Spain: Manuel Posada

Areas of Interest- Research
Epidemiology
Risk factors
Recurrence risk
Prenatal screening
Genetic diagnosis
Brain development
Behavioral development

Areas of Interest- Methodology
Development of common measures
Building a European data Repository
Comparative sampling strategies and risk populations
Population-based registries

Areas of Interest- Practice
Diagnostic approaches
Formulation of practice standards for high-risk groups
Genetic counseling
Intervention
# RELEVANT PROJECTS

<table>
<thead>
<tr>
<th>Status</th>
<th>Country</th>
<th>PI</th>
<th>Project title</th>
<th>Current N</th>
<th>Total N</th>
<th>Topic key words</th>
<th>Group</th>
<th>Methodology</th>
<th>Project start</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-scale</td>
<td>UK</td>
<td>M.H. Johnson</td>
<td>British Autism Study of Infant Siblings (BASIS)-UK research network</td>
<td>188</td>
<td>260</td>
<td>Brain, social, attention, motor, BAP, genetics, intervention</td>
<td>ASD siblings</td>
<td>Genetic, EEG, MRI, Behavior, standardized measures, questionnaire</td>
<td>May-08</td>
</tr>
<tr>
<td></td>
<td>Belgium</td>
<td>H. Roeyers</td>
<td>Following up infants and toddlers at risk for ASD</td>
<td>55</td>
<td>100</td>
<td>Social development, attention</td>
<td>ASD siblings</td>
<td>EEG, Behavior</td>
<td>Jan-07</td>
</tr>
<tr>
<td></td>
<td>Sweden</td>
<td>U. Adén, S. Bölte</td>
<td>Follow up of extremely preterm infants at 6 years- a population based study in</td>
<td>109</td>
<td>250</td>
<td>Brain, cognition, IQ</td>
<td>Preterm</td>
<td>Standardized measures, questionnaire, MRI</td>
<td>Jan-04</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Stockholm (EXPRESS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sweden</td>
<td>S. Bölte, T. Falck-Y., G. Gredebäck</td>
<td>Early Autism Sweden (EASE)</td>
<td>0</td>
<td>100</td>
<td>Non-verbal communication, autonomous system, motor function, brain</td>
<td>ASD siblings</td>
<td>NIRS, eye tracking, observation scales, questionnaires</td>
<td>Jan-11</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0</td>
<td>30</td>
<td></td>
<td>Preterm</td>
<td>Questionnaire, tests</td>
<td>Jan-12</td>
</tr>
<tr>
<td></td>
<td>Italy</td>
<td>T. Farroni</td>
<td>Predictors at birth and in premature babies</td>
<td>3</td>
<td>TBD*</td>
<td>ASD predictors</td>
<td>ASD siblings</td>
<td>NIRS, behavioral</td>
<td>Jan-10</td>
</tr>
<tr>
<td>Pilot</td>
<td>Czech Republic</td>
<td>M. Hrdlicka</td>
<td>New approaches to early diagnostics of autism</td>
<td>5</td>
<td>12</td>
<td>Genetics</td>
<td>ASD siblings</td>
<td>Karyotyping, screening, CNV analysis</td>
<td>2011</td>
</tr>
<tr>
<td>Israel</td>
<td>N. Yirmiya</td>
<td>Association between pre-term birth and ASD spectrum disorders and the BAP</td>
<td>25</td>
<td>100</td>
<td>ASD phenotype</td>
<td>Preterm</td>
<td>Observation, Interview</td>
<td>Dec-09</td>
<td></td>
</tr>
<tr>
<td>Planned</td>
<td>Israel</td>
<td>D. Mankuta</td>
<td>Prenatal clues for Autism in high risk groups</td>
<td>0</td>
<td>300</td>
<td>Biochemical, sonographic, genetic markers</td>
<td>ASD siblings</td>
<td>TBD*</td>
<td></td>
</tr>
<tr>
<td>Portugal</td>
<td>A. Vicente</td>
<td>Earliest signs of autism</td>
<td>0</td>
<td>200</td>
<td>Genetics</td>
<td></td>
<td>CGH array, questionnaires</td>
<td>2012</td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td>M. Posada</td>
<td>Spanish ASD sibling cohort: Feasibility study</td>
<td>0</td>
<td>TBD*</td>
<td>feasibility, epidemiology</td>
<td>ASD siblings</td>
<td>Screening</td>
<td>Oct-11</td>
<td></td>
</tr>
</tbody>
</table>
RELEVANT PUBLICATIONS


