

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

TBA* = to be determined

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

RELEVANT PUBLICATIONS

- Gamliel, I., Yirmiya, N., Jaffe, D. H., Manor, O., & Sigman, M. (2009). Developmental trajectories in siblings of children with autism: cognition and language from 4 months to 7 years. *Journal of Autism and Developmental Disorders*, 39, 1131-1144.
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- Hancarova M., Drabova J., Zmitkova Z., Vlckova M., Hedvicakova P., Novotna D., Vlckova Z., Vejvalkova S., Marikova T., & Sedlacek Z. (2010) Array comparative genome hybridization in patients with developmental delay: two example cases. *New Biotechnology*, Oct 20. [Epub ahead of print]
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- Lerer, E., Levi, S., Israel, S., Yaari, M., Nemanov, L., Mankuta, D., Nurit, Y., & Ebstein RP. (2010). Low CD38 expression in lymphoblastoid cells and haplotypes are both associated with autism in a family-based study. *Autism Research*, 3,293-302.
- Ricardo Canal-Bedia et al. (2011). Modified Checklist for Autism in Toddlers: Cross-Cultural Adaptation and Validation in Spain. *Journal of Autism and Developmental Disorders*, 41, 1342-1351.
- Seidman, I., Yirmiya, N., Alon, R., Ben Yitzhak, N., Lord, C., & Sigman, M. (2010). Diagnostic outcomes in school age siblings of children with autism. *International Public Health Journal*, 2, 113-124.
- Spiroski, M., Trajkovski, V., Trajkov, D., Petlichkovski, A., Efinska-Mladenovska, O., Hristomanova, S., Djulejic, E., Paneva, M., & Bozhikov, J.(2009). Family analysis of immunoglobulin classes and subclasses in children with autistic disorder. *Bosnian Journal of Basic Medical Sciences*, 9, 283-289.
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