

# COST

Domain Committee "BMBS"

## COST Action BM1004

Start Date 15/12/2010

Enhancing the Scientific Study of Early Autism (ESSEA)

## MONITORING PROGRESS REPORT

**Reporting Period:** from (April 2011 – April 2012)

This Report is presented to the relevant Domain Committee.  
It contains three parts:

- I. Management Report** prepared by the Grant Holder
- II. Scientific Report** prepared by the Chair of the Management Committee of the Action
- III. Previous versions of the Scientific Report;** i.e., part II of past reporting periods

The report is a "cumulative" report, i.e. it is updated annually and covers the entire period of the Action.

Confidentiality: the documents will be made available to the public via the COST Action web page except for chapter *II.D. Self evaluation*.

Based on the monitoring results, the COST Office will decide on the following year's budget allocation.

### **Executive summary (max.250 words):**

The Action fulfilled its goals for 2011. It funded 6 STSMs for ESRs involving 8 labs from 6 participating countries. A joint MC meeting and meetings of all 4 Work Group (WGs) was held in Padua, Italy in September 2011. WGs have continued their work via conference calls. Each WG completed a 'mapping exercise' to summarise recent and ongoing studies relevant to their topic area and have developed a range of activities to take this work forward. A dedicated Action website was launched: <http://www.cost-essea.com/>. A second joint MC and WG meeting is scheduled for Tours, France in May 2012. 4 STSMs were funded in the first of 2 calls due in 2012. A training school is to be held jointly with a Marie Cure Initial Training Network in October 2012 and was over-subscribed. The support of COST was acknowledged in several publications by Action participants and COST Action members have presented (or are due to present) in several international conferences, including several branded as 'COST Action' participation. Several Action participants have mentioned their involvement in the COST Action in successful grant from national organisations. The Action featured strongly and several Action participants from 3 participating countries were involved in an Innovative Medicines Initiative (IMI) award announced in March 2012 worth €29.6 million: <http://www.eu-aims.eu/home/>. The Action featured on COST stories on 2<sup>nd</sup> April 2012 to the UN sponsored mark World Autism Awareness day: [http://www.cost.eu/about\\_cost/cost\\_stories/Autism](http://www.cost.eu/about_cost/cost_stories/Autism).

## I. Management Report prepared by the Grant Holder



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

### • Action details:

**CSO Approval:** 25/05/2010  
**Entry into force:** 22/07/2010

**End date:** 14/12/2014  
**Extension:**

• **Objectives** A wide number of scientific methodologies and disciplines are relevant to the study of early autism, including studying genetically 'at risk' siblings; the development of novel neuroimaging techniques; and developing and testing screening instruments and interventions. The lack of a forum to enhance the scientific synergies between these strands of basic and applied research has hindered progress. This Action will create a network to enable developments in clinical practice and policy to be informed by cutting edge science and a rigorous evidence-base, significantly improving quality of life for individuals with autism, their families and broader European society. Increased and earlier recognition has impacted across Europe in terms of demand for diagnostic services and interventions. Current health care systems across Europe are very variable in terms of their expertise and capacity to support families with young children with autism, often leading to marginalisation.

### • Parties:

Austria	Greece	Poland 22/07/2010
Belgium 30/09/2010	Hungary 12/05/2011	Portugal 28/10/2010
Bulgaria	Iceland 17/11/2010	Romania 21/10/2010
Croatia	Ireland 08/09/2010	Serbia
Cyprus	Israel 22/07/2010	Slovakia
Czech Rep. 17/12/2010	Italy 22/07/2010	Slovenia
Denmark 08/12/2010	Latvia	Spain 22/07/2010
Estonia	Lithuania	Sweden 21/10/2010
Finland 28/09/2010	Luxembourg	Switzerland
FYR of Macedonia 12/10/2010	Malta	Turkey
France 20/09/2010	Netherlands 08/10/2010	United Kingdom 22/07/2010
Germany 14/09/2010	Norway 17/09/2010	

- **Intentions to accept:** Austria

### Other participants:

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### Action Web site:

<http://www.cost-essea.com/>

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• **Working Groups** (*list of WGs and names and affiliations of participants*)

<b>BM 1004: Enhancing the Scientific Study of Early Autism (ESSEA)</b>
<b>Chair:</b> Tony Charman (UK)
<b>Vice-Chair:</b> Herbert Roeyers (Belgium)
<b>WG1: The study of genetically 'at risk' younger siblings of an older child with a diagnosis.</b>
<b>Chair:</b> Sven Bölte (Sweden)
<b>Co-Chair:</b> Chantal Kemner (Netherlands)
Teresa Farroni (Italy)
Nurit Yirmiya (Israel)
Aurora Arghir* (Romania)
Magdalena Budisteanu* (Romania)
Astrid Vincente (Portugal)
Louise Gallagher* (Ireland)
Manuel Posada (Spain)
Markéta Havlovicová (Czech Republic)
David Mankuta (Israel)
Vladimir Trajkovski (Former Yugoslav Republic of Macedonia)
Jan Buitelaar (Netherlands)
<b>WG2: The application of novel methods for studying young children and infants.</b>
<b>Chair:</b> Terje Falck-Ytter* (Sweden)
<b>Co- Chair:</b> Catherine Barthelemy (France)
Claus von Hofsten (Norway)
Anneli Kylliäinen* (Finland)
Gerardo Herrera (Spain)
Guiomar Oliveira (Portugal)
Silvana Markovska* (Former Yugoslav Republic of Macedonia)
Eija Karna (Finland)
Marie Gomot (France)
Andrei Miu (Romania)
Simon Baron-Cohen (UK)
Gyorgy Gergely (Hungary)
Erő Téglás (Hungary)*
Agnes Kovacs (Hungary)*
Peter Marschik (Austria)
<b>WG3: Testing how well screening instruments work in prospectively identifying cases.</b>
<b>Chair:</b> Emma van Daalen* (Netherlands)
<b>Co- Chair:</b> Synnve Scholberg (Norway)
Michele Noteradaeme (Germany)
Ricardo Canal Bedia (Spain)
Rafal Kawa* (Poland)
Evald Saemundsen (Iceland)
Sigrídur Jónsdóttir (Iceland)
Paul Magnussen (Iceland)
Ingiborg Georsdóttir (Iceland)
Filippo Muratori (Italy)

Roberto Militerni (Ital)
Paola Venuti (Italy)
Irma Moilanen (Finland)
Stepanka Beranova (Czech Republic)
Michal Hrdlicka (Czech Republic)
Martin Holtmann (Germany)
Nada Pop-Jordanova* (Former Yugoslav Republic of Macedonia)
Tatjana Zorcec* (Former Yugoslav Republic of Macedonia)
Rutger Van Der Gaag (Netherlands)
Annika Melinder* (Norway)
<b>WG4: Testing early intervention approaches through rigorous controlled trials.</b>
<b>Chair:</b> Helen McConachie (UK)
<b>Co- Chair:</b> Petra Warren* (Belgium)
Iris Oosterling* (Netherlands)
Joaquin Fuentes (Spain)
Bernadette Rogé (France)
Jonathan Green (UK)
Luise Poustka* (Germany)
Michele Noterdaeme (Germany)
Mikael Heimann (Sweden)
Anett Kaale (Norway)
Judith Sinzig (Germany)
<b>* Early Stage Researcher (ESR; less than 8 years from PhD)</b>

## I.B. Management Committee member list

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## I.C. Overview activities and expenditure

### Meetings

Meeting Type	Date	Place	Cost Total
Core Group meeting	09/02/2012	COST Office, Brussels	<b>3,600</b>
Joint MC and WG meetings	29-30/05/2012	Tours, France	<b>35,000</b>
WG meetings	04-05/09/2012	COST Office, Brussels	<b>12,500</b>

### STSM

Beneficiary	Date	Place	Cost Total
Antonio Narzisi	Oct 2012	Manchester, UK	1,550
Erica Salomone	Sept 2012	Bonn, Germany	1,560
Karolin Gruber	Nov 2012	Manchester, UK	1,120
Lateicia Roché	Aug 2012	Uppsala, Sweden	2,400
4 further ESRs in 2 <sup>nd</sup> call			5,370
			<b>12,000</b>

### Workshops

Title	Date	Place	Cost Total
	From To	From To	
			<b>0</b>

### General Support Grants

Beneficiary	Date	Cost Total
		<b>0</b>

### Schools

Title	Date	Place	Cost Total
Novel Methods in Developmental Research	01-05/10/2012	Uppsala, Sweden	<b>22,400</b>

### Dissemination

Title	Date	Place	Cost Total
Software			<b>1,000</b>
Logistics for website			<b>2,000</b>

### Others

<b>OESRA</b>	<b>2,000</b>
<b>FSAC</b>	<b>13,575</b>

**Action Total : 104,075**

## **II. Scientific Report**

### **II.A. Innovative networking**

Each of the 4 WorkGroups (WG) has completed a 'mapping' of current activity in Europe in each area of the Action's activities (i) the study of populations at-risk for autism; (ii) groups using new technologies with infants and preschoolers; (iii) prospective screening studies; and (iv) psychosocial early intervention studies and these are available from the Action website (<http://www.cost-essea.com/>). Following on from this and the subsequent WG meetings in Padua, September 2011 and conference calls each WG has developed a plan of activities for 2011 and 2012 which are also available via the website. These will lead both to novel data collection and publications by the end of 2012. Initial findings will be presented at the forthcoming IACAPAP (<http://www.resotel.eu/site/-Home-page->) and IRIA (<http://www.iria2012-tours.fr/>) meetings.

The Action featured strongly and 6 Action participants from 3 countries (UK, Netherlands, Sweden) were involved in an Innovative Medicines Initiative (IMI) award announced in March 2012 with FP7 funding (grant agreement n° 115300) and including EFPIA companies' in kind contribution and from the Autism Speaks resulting in a total of €29.6 million. <http://www.eu-aims.eu/home/>.

National grants where participation in the Action was mentioned in the application:

- Astrid Vicente (Portugal), Guiomar Oliveira (Portugal). "Identifying the early signs of Autism Spectrum Disorder - integration of behavioral and genetic information for early autism detection". Fundação para a Ciência e Tecnologia. €119,755 (2012 – 2014).
- Michele Noterdaeme (Germany). Grant from the Hans Seidl Stiftung in München, €50,000 (2011 – 2013).
- Anneli Kylliäinen (Finland). "Attention and affective motivational responses to eye contact in young children with severe autism". The Academy of Finland, €290,000 (2011 – 2014).
- Herbert Roeyers (Belgium). "Autism spectrum disorders in extremely preterm children". The Research Foundation – Flanders. €296,000 (2012 – 2016).

### **II.B. Inter-disciplinary networking**

The Action involves, psychologists, psychiatrists, paediatricians, neuroscientists and epidemiologists and as such represents a truly interdisciplinary research network. Additional collaborations have begun in participating countries between Action participants and robotics and artificial intelligence scientists (not yet directly involved in the Action).

### **II.C. New networking**

Hungary joined the Action in May 2011 and Austria has recorded an intention to join, following MC approval in February 2012.

6 STSMs were conducted all by ESRs in 2011. The first call of 2012 resulted in 4 STSMs for 2012 being funded (again all by ESRs). A 2<sup>nd</sup> call will follow later in the year.

17 applications were made by (16 by ESRs) to the Training School on novel methods/techniques to be held in October 2012. 12 places will be funded with the rest placed on a waiting list until funding for 2012 is finalised.

A joint meeting was held in December 2011 in Amsterdam with the BMBS COST Action BM0905 *European Network for the Study of Gilles de la Tourette Syndrome*.

The 2012 Training School is being jointly funded by the Action and a Marie Curie Initial Training Network to increase participation of ESRs (both those funded by the Action and by the MC funds) and to increase the number of invited international speakers to the meeting.

Representatives of the parent organisation Autism Europe attended the joint MC and WG meeting in Padua, September 2011 and will be involved again at the joint MC and WG meeting in Tours, in May 2012.

*Further information on involvement of ESRs:* 3 out of 4 WGs are (co-)lead by an ESR; over half of the participants in the Padua joint MC and WG meeting were ESRs; and ESRs are leading on over half of the planned WG activities for 2011/2012.

*Further information on involvement of female scientists:* Continuing from the first year of the Action female researchers were strongly represented in the Action:

- Of the 12 'senior' Core Group positions (Chair, Vice-Chair, co-leads of 4 Work Groups, STSM co-ordinator and website co-ordinator) 8 were held by female researchers
- Of the 6 STSMs funded in 2011 5 were taken up by female researchers

The dedicated Action website was launched in the Summer of 2011 and is due to be updated/upgraded in the Summer of 2012. It contains information on the WG activities and other Action activities: <http://www.cost-essea.com/>.

The Action featured on COST stories on 2<sup>nd</sup> April 2012 to the UN sponsored mark World Autism Awareness day: [http://www.cost.eu/about\\_cost/cost\\_stories/Autism](http://www.cost.eu/about_cost/cost_stories/Autism). The Action Chair worked with Alessandra Paccamiccio (COST Office Public Relations and Communications Officer) on the story.

The Action has been represented at the following (including forthcoming) conferences:

- **Petra Warreyn** (Belgium), **Mayada Elsabbagh** (UK), **Catherine Barthélemy** (France), **Emma Van Daalen** (Netherlands), **Chantal Kemner** (Netherlands), **Jan Buitelaar** (Netherlands). Symposium: "Early diagnosis of autism: a state of affairs and future directions". 15<sup>th</sup> European Conference on Developmental Psychology, August 2011, Bergen, Norway.
- Innovative Research in Autism (IRIA) conference, Tours, France, 30<sup>th</sup> May to 2<sup>nd</sup> June 2012. **Contributions are from all 4 WG leads, Chair and Vice Chair.**
- International Association for Child and Adolescent Psychiatry and Allied Professionals (IACAPAP) 20th World Congress, Paris, France, 2<sup>st</sup> to 25<sup>th</sup> July 2012. Organised by members of WG4. **Judith Sinzig** (Germany), **Helen McConachie** (UK)
- Submission including **9 COST participants listed as members/supporters** accepted as an Special Interest Group on "Knowledge translation in early identification and intervention" at the International Meeting for Autism Research (IMFAR), Toronto, Canada, May 2012.
- **Herbert Roeyers** was invited to present the ESSEA project on the Scientific Day of the French Autism Resource Centers in Paris on March 15, 2012

5 publications from 3 Action members mentioned support from the BM1004 COST Action in the acknowledgements of peer reviewed papers.

The Action has directly and indirectly led to leverage of both national and FP7 funding (see Section II. A above for details).

### **III. Previous scientific report(s)**

#### **II.A. Innovative networking**

Following the kick-off MC meeting in December 2010 we have undertaken a 'mapping' exercise to document the current and planned activities being undertaken in the 4 areas of science relevant to each Work Group: (i) the study of populations at-risk for autism; (ii) groups using new technologies with infants and preschoolers; (iii) prospective screening studies; and (iv) psychosocial early intervention studies. These will be presented at the expanded Core Group meeting in Brussels on 12<sup>th</sup> April 2011 and form the basis for planned Year 1 and 2 activities of the Action.

Several COST MC members are involved in a bid to the Innovative Medicines Initiative (EU/EFPIA) 'Translational endpoints in autism' (decision July 2011).

#### **II.B. Inter-disciplinary networking**

The Action involves, psychologists, psychiatrists, paediatricians, neuroscientists and epidemiologists and as such represents a truly interdisciplinary research network.

#### **II.C. New networking**

27 scientists attended the kick-off meeting in December 2010. The Action involves 57 scientists from 20 countries. Other scientists active in the field have been invited to join. Since this meeting one country has joined the Action (Hungary).

18 of the 57 scientists (31.6%) are ESRs. 27 (47.4%) of the scientists are female and 28 (51.9%) are male. Each of the Work Groups has one ESR as Chair or Co-Chair and of the 8 Chairs/Co-Chairs of Work Groups 6 are female (75%).

A senior MC member and 2 ESRs have formed a Committee to oversee and review applications and allocation of STSMs. 4 STSMs are due to be held in Year 1 and will be advertised in May and completed by December 2011. STSMs will be reserved for ESRs.

The joint MC and 4 WG meetings are scheduled to take place in Padua, Italy on 19/20 September 2011.

Two groups working in relevant technical areas (from Romania and Hungary) have been invited to join Action and we awaiting their applications via their CNCs.

The MC has agreed a publications and dissemination strategy to ensure that the Action has visibility and presence in the scientific field as soon as possible. The MC has invited the largest parent advocacy organisation for autism to join the Action as a partner (Autism Europe) and they have agreed (costs to be met through the Action budget). The MC has also invited the largest USA autism charity with a European Development Officer (Autism Speaks) to join the Action as a partner (costs to be met by Autism Speaks).