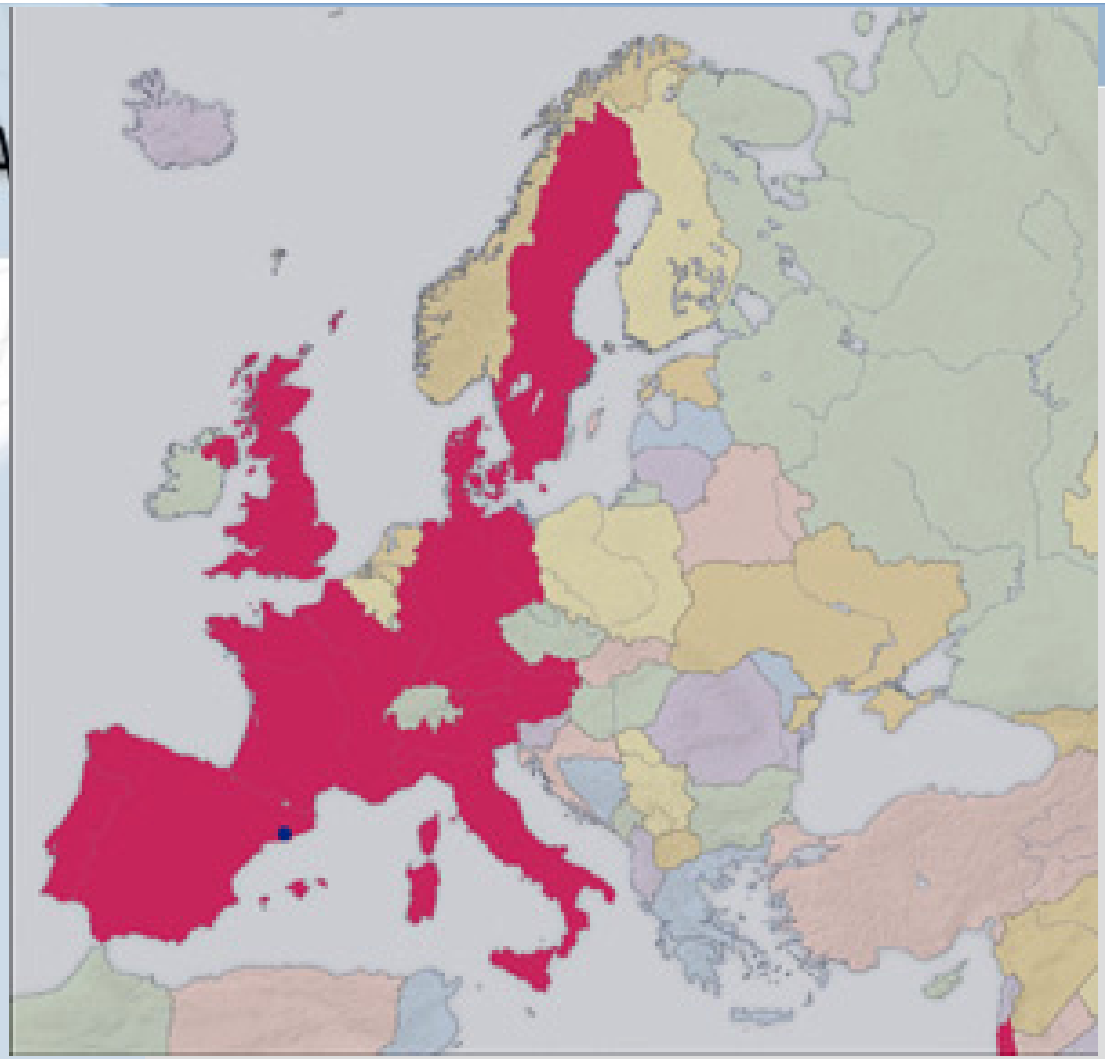
EMSA-SG: the first 10 years (1999 – 2009)



EMSA Study Sites

Innsbruck	Werner Poewe, Gregor K Wenning
Aarhus	Karen Østergaard
Bordeaux	Francois Tison
Toulouse	Olivier Rascol
Bonn	Thomas Klockgether
Kiel	Günther Deuschl
Marburg	Wolfgang Oertel
Tübingen	Thomas Gasser
Petach-Tiqva	Ruth Djaldetti
Tel Aviv	Nir Giladi
Milano 1	Angelo Antonini
Milano 2	Alberto Albanese
Naples	Paulo Barone
Rome	Giuseppe Meco
Lisboa	Cristina Sampaio
Lund	Håkan Widner
Barcelona	Eduardo Tolosa
Santander	Jose Berciano
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EMSA-SG

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EMSA-SG Steering Board June 2009

D Brooks

CJ Fowler

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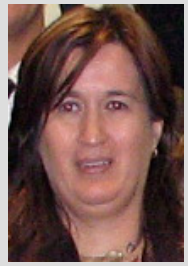
A Lees



C Sampaio

C Mathias

W Oertel

N Quinn

E Tolosa

O Rascol

F Tison

EMSA-SG: Milestones

- 01 / 1999 First meeting in Innsbruck
- 06 / 2000 FP5 grant approval (560.000 Euro)
- 12 / 2001 UMSARS established
- 01 / 2002 Launch of EMSA Registry
- 12 / 2002 Launch of natural history study
- Since 2003: Clinical projects (SLE_EMSA, Cognition, Diagnostic criteria, Neuroimaging), Clinical trials (MEMSA & rhGH), Genetic studies, EMSA website

EMSA Website

www.emsa-sg.org

EMSA Registry: Minimal Data Set

EMSA-SG REGISTRY BASELINE MDS

Patient code ▢▢–▢▢▢

A. Personal Data

		(dd.mm.yyyy)
1.	Date of examination	|_||_|.|_||_|.|_||_||_||_|
		(dd.mm.yyyy)
2.	Date of data entry	|_||_|.|_||_|.|_||_||_||_|
3.	Age	|___|
4.	Hoehn & Yahr stage	|__|
5.	Clinical diagnosis of	
	- MSA-P[1]	
	- suspected	Yes |_| No |_|
	- definite	Yes |_| No |_|
	- MSA-C[1]	
	- suspected	Yes |_| No |_|
	- definite	Yes |_| No |_|
		(mm.yyyy)
6.	Time of symptom onset[2]	|_||_|.|_||_||_||_|
		(If month not known, enter NK for month)
7.	Family history[3]	Yes |_| No |_|
	If yes, please specify	_____
8.	Serum acquired	Yes |_| No |_|
9.	CSF acquired	Yes |_| No |_|
10.	DNA available	Yes |_| No |_|

EMSA-SG REGISTRY BASELINE MDS

Patient code ▢▢–▢▢▢

B. Current drug history

List all medications (prescription and over-the-counter, including vitamins) taken within the past three months. Please state total daily dose (TDD) using appropriate units (e.g. mg), route (e.g. **oral/rectal/sc/im/iv**), and presence or absence of clinically significant benefit and side effects as judged by investigator.

B.1 Antiparkinsonian Drugs

B.1.1 MAO-B-inhibitors |_| Yes |_| No |_| Unknown

Drugs (generics)	TDD (Unit) / Route	Clinical benefit* yes	no	unkn.	Side effects** yes	no	unkn.
Selegeline	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|
Rasagiline	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|
Others:							
_____	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|
_____	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|
_____	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|

* if yes, please specify _____

** if yes, please specify _____

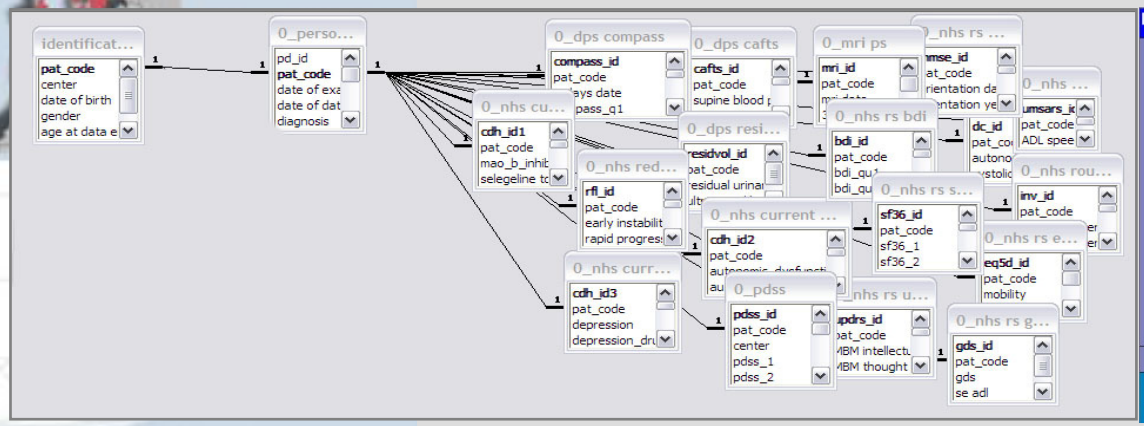
B.1.2 COMT-inhibitors |_| Yes |_| No |_| Unknown

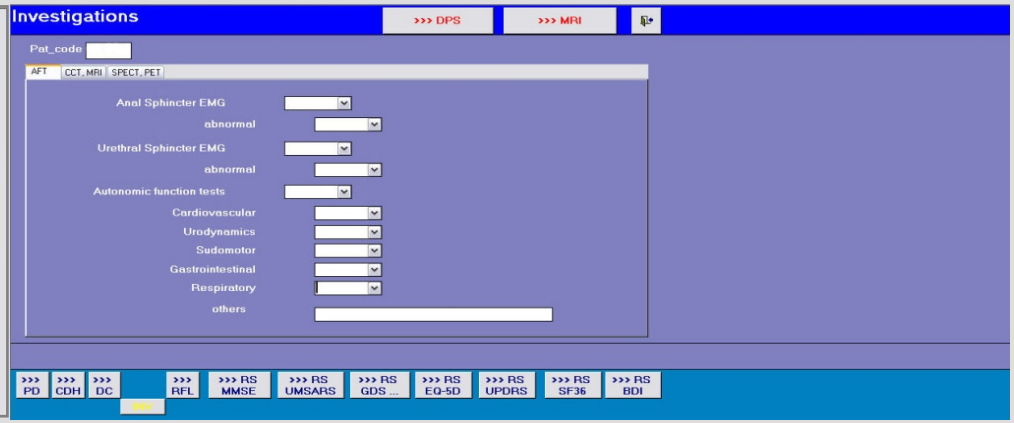
Drugs (generics)	TDD (Unit) / Route	Clinical benefit* yes	no	unkn.	Side effects** yes	no	unkn.
Entacapone	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|
Tolcapone	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|
Others:							
_____	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|
_____	_____(___)/_____	|_|	|_|	|_|	|_|	|_|	|_|

* if yes, please specify _____

** if yes, please specify _____

EMSA Registry: Central Database





- **Data protection:**
  - **Patient codes (saved externally)**
  - **Database and user interface password protected**
- **Quality control:**
  - **User interface**
  - **Plausibility check**
  - **Data check on random samples**

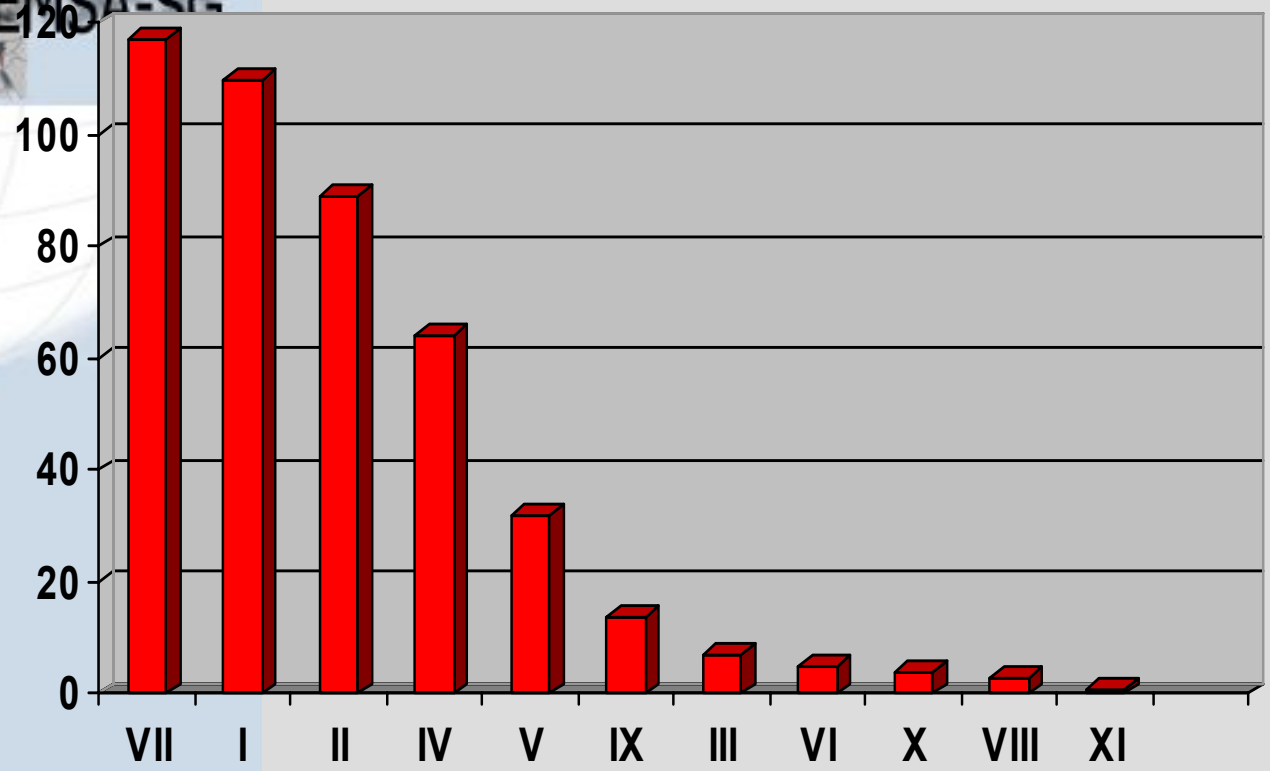
EMSA Registry: Study population

Country (n)	Age (years)	dd (years)	m:f Ratio	FA (%)
Europe (443)	**57.5 ± 9.2**	**5.85 ± 3.82**	**1 : 0.96**	**4.9**
Denmark (15)	58.9 ± 7.7	5.60 ± 3.55	1 : 2	0
Germany (44)	57.4 ± 8.4	4.30 ± 3.28	1 : 0.80	2.3
England (61)	53.8 ± 8.0	5.52 ± 1.89	1 : 1.03	5.0
France (73)	60.3 ± 9.2	6.17 ± 4.19	1 : 1.20	2.7
Israel (87)	57.7 ±10.7	6.59 ± 4.90	1 : 0.90	10.3
Italy (40)	58.5 ± 8.9	4.73 ± 2.75	1 : 1.20	2.6
Austria (60)	57.4 ± 9.0	6.04 ± 3.48	1 : 1	3.9
Portugal (13)	58.8 ± 8.9	5.92 ± 3.36	1 : 0.30	0
Sweden (15)	59.6 ± 8.3	8.66 ± 6.23	1 : 0.67	20.0
Spain (35)	56.7 ± 7.8	5.64 ± 2.60	1 : 0.75	0

EMSA Registry: Diagnosis

Country (n)	Consensus Criteria (%)			
	MSA-P	MSA-C	possible	probable
Europe (443)	**68.4**	**31.6**	**23.7**	**76.3**
Denmark (15)	73.3	26.7	40.0	60.0
Germany (44)	68.2	31.8	18.2	81.8
England (61)	67.2	32.8	23.0	77.0
France (73)	75.3	24.7	20.5	79.5
Israel (87)	72.4	27.6	31.0	69.0
Italy (40)	67.5	32.5	35.0	65.0
Austria (60)	71.7	28.3	20.0	80.0
Portugal (13)	92.3	7.7	46.2	53.8
Sweden (15)	66.7	33.3	13.3	86.7
Spain (35)	31.4	68.6	2.9	97.1

EMSA Registry: Clinical Spectrum



I park, atax, dysaut, pyram
II park, atax, dysaut
III park, atax, pyram
IV park, dysaut, pyram
V atax, dysaut, pyram
IV park, atax
VII park, dysaut
VIII park, pyram
IX atax, dysaut
X atax, pyram
XI dysaut, pyram

Revised MSA Criteria
International Consensus Conference

EMSA-SG

Approval of NIH Grant for Revision of MSA Consensus Criteria 10 / 2006
(NINDS Grant 1 R13 NS055459)

14 EMSA Publications

EMSA-SG

Koellensperger et al. Mov Disord 2009 in press.

Dodel et al. Mov Disord 2009 in press.

Scholz et al. Ann Neurol 2009; 65: 610-4

Petzold et al. J Neurol Sci. 2009 ; 279: 76-9

Gilman et al. Neurol 2008; 71: 670-6.

Koellensperger et al. Mov Disord 2008; 23: 1093-1099.

Koellensperger et al. Eur J Neurol 2007; 14: 66-72.

Holmberg et al. Mov Disord 2007; 22: 1138-44

Geser et al. Mov Disord 2006; 21: 179-86.

Ozawa et al. J Neurol Neurosurg Psychiatry 2006; 77: 464-7.

Schrag et al. Mov Disord 2006; 21: 809-15.

Geser et al. J Neural Transm 2005; 112: 1677-86.

Healy et al. Mov Disord 2005; 20: 1338-43.

Kamm et al. Brain 2005; 128: 1855-60

+ 29 Abstracts

Cooperation with North American MSA Study Group - Coordinators -

C Shults 2003-2007

P Low 2007-

Cooperation with Japanese MSA Consortium - JAMSAC Coordinator

S Tsuji

EMSA-SG: goals for the next 10 years

- Elucidate aetiopathogenesis
- Develop better transgenic models
- Improve surrogate markers / early diagnosis
- Identify candidate neuroprotective agents
- Conduct phase ii / iii intervention trials