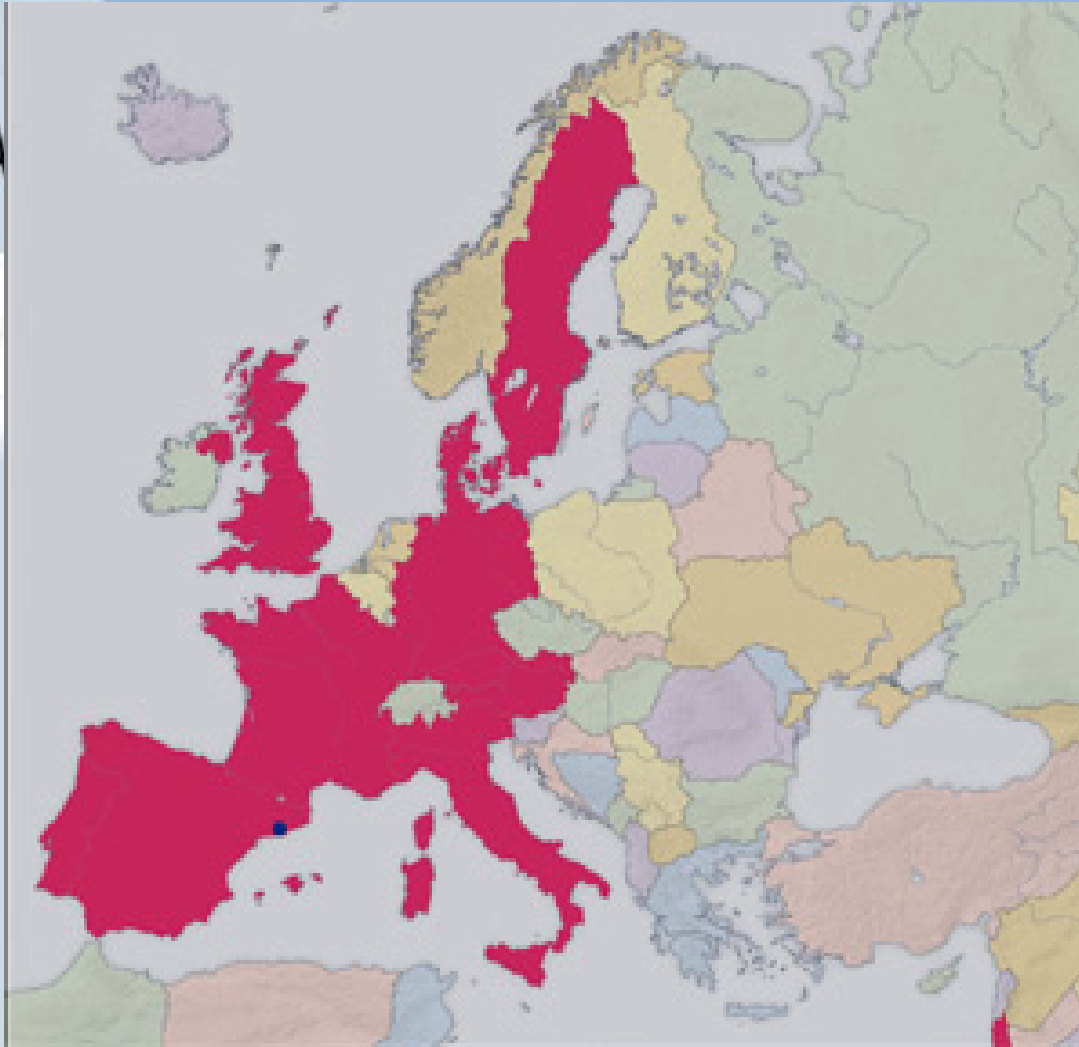


# EMSA-SG: the first 10 years (1999 – 2009)



## 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
	Cardiff	Huw Morris
	London	Andrew J. Lees



### Coordinators



Werner Poewe  
Innsbruck AUSTRIA



Gregor K Wenning  
Innsbruck AUSTRIA

### EMSA Post-Doc



Susanne Duerr  
Innsbruck AUSTRIA

## EMSA-SG Steering Board June 2009



D Brooks



CJ Fowler



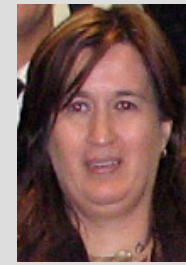
T Gasser



T Klockgether



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**





## European Multiple System Atrophy Study Group

[▶ HOME](#) [▶ MSA](#) [▶ MEMBERSHIP](#) [▶ RESEARCH](#) [▶ LINKS](#) [▶ LOGIN](#)

### Country specific patient information

[Danmark](#) | [Deutschland](#) | [England](#) | [Espania](#) | [France](#) | [Israel](#) | [Italia](#) | [Österreich](#) | [Portugal](#) | [Slovenia](#) | [Sweden](#)

**The European Multiple System Atrophy Study Group (ORGANIGRAM)** was founded in January 1999. It represents a consortium of scientific investigators from academic and research centres in Europe and Israel who are committed to clinical trial activity and other research studies aimed at improving the treatment of MSA. To this end, EMSA-SG aims to advance knowledge about the aetiology and pathogenesis of MSA. Furthermore, EMSA-SG will work with government and industry sponsors to develop and implement novel therapeutic interventions in MSA. EMSA-SG is committed to the principles of open and full scientific communication. EMSA-SG is also interested in educating professionals and the public by providing scientific and medical information about MSA. EMSA-SG intends to pursue these objectives globally in close cooperation with the North American MSA Study Group (NAMSA-SG, Coordinating Office: Rochester, Minnesota, USA), the Japanese MSA Study Group (JAMSA-SG, Coordinating Office: Tokyo) and the Chinese MSA Study Group (CNMSA-SG, Coordinating Office: Beijing).

### **SPONSORED BY**



# EMSA Registry: Minimal Data Set

## EMSA-SG REGISTRY BASELINE MDS

Patient code  -

### A. Personal Data

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

3

## 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*			Side effects**		
		yes	no	unkn.	yes	no	unkn.
Selegiline	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rasagiline	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others:	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* if yes, please specify \_\_\_\_\_

\*\* if yes, please specify \_\_\_\_\_

**B.1.2 COMT-inhibitors**  Yes  No  Unknown

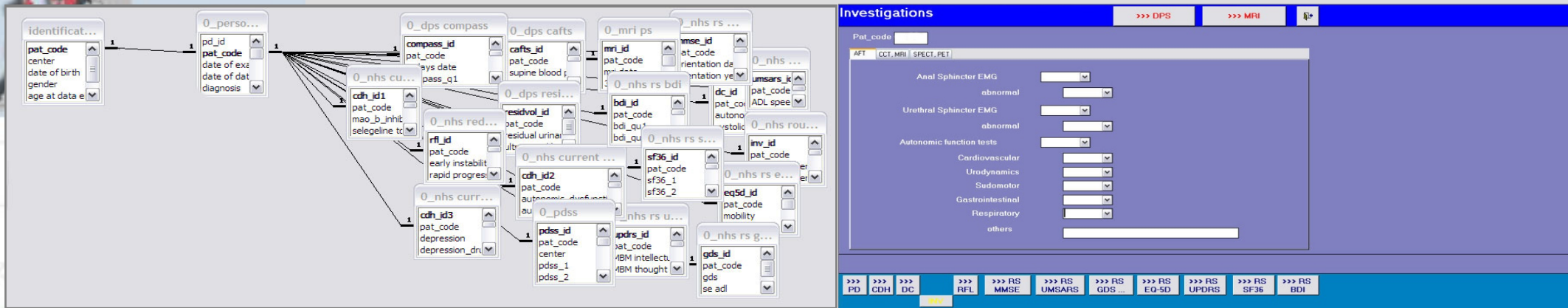
Drugs (generics)	TDD (Unit) / Route	Clinical benefit*			Side effects**		
		yes	no	unkn.	yes	no	unkn.
Entacapone	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tolcapone	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others:	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	____(____)/____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* if yes, please specify \_\_\_\_\_

\*\* if yes, please specify \_\_\_\_\_


4

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

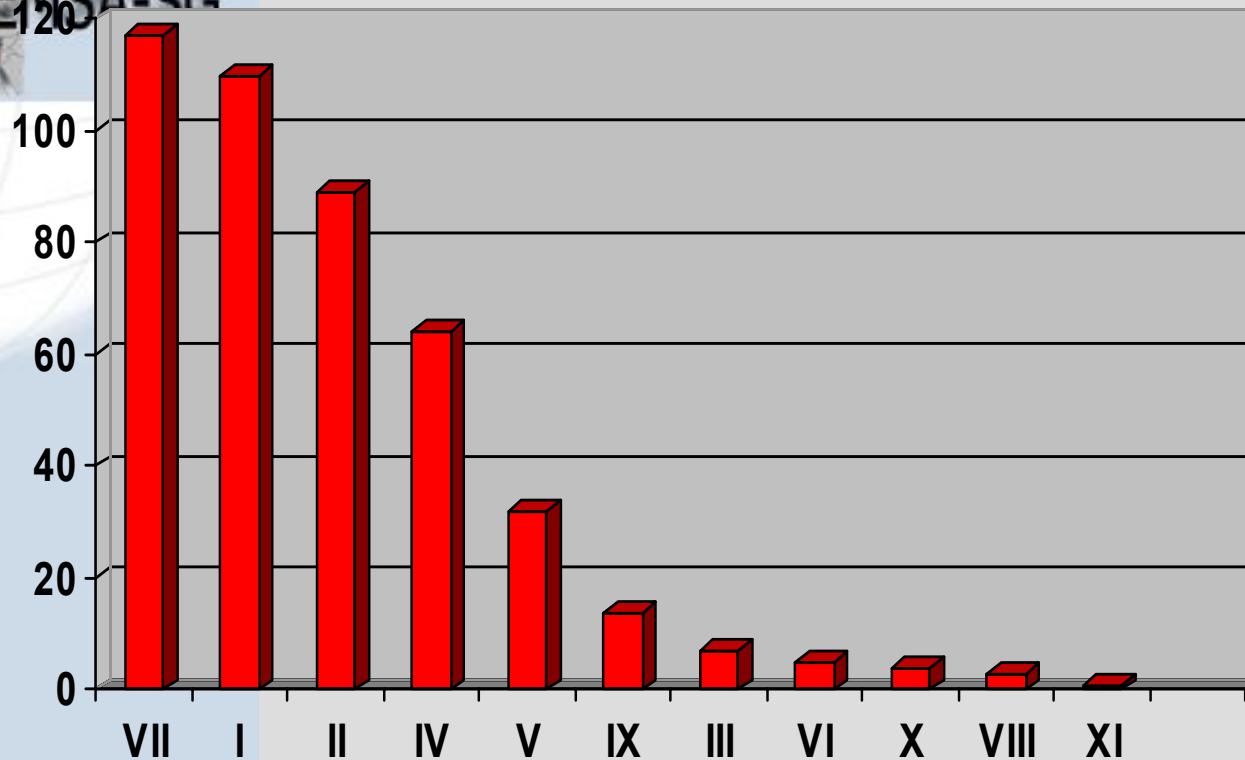
# EMSA Registry: Diagnosis



Country (n)	Consensus Criteria (%)			
	MSA-P	MSA-C	possible	probable
<b>Europe (443)</b>	<b>68.4</b>	<b>31.6</b>	<b>23.7</b>	<b>76.3</b>
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



Boston 04 2007



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



# 14 EMSA Publications

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**