

# Resoconto attività scientifica 2020 GdS MM

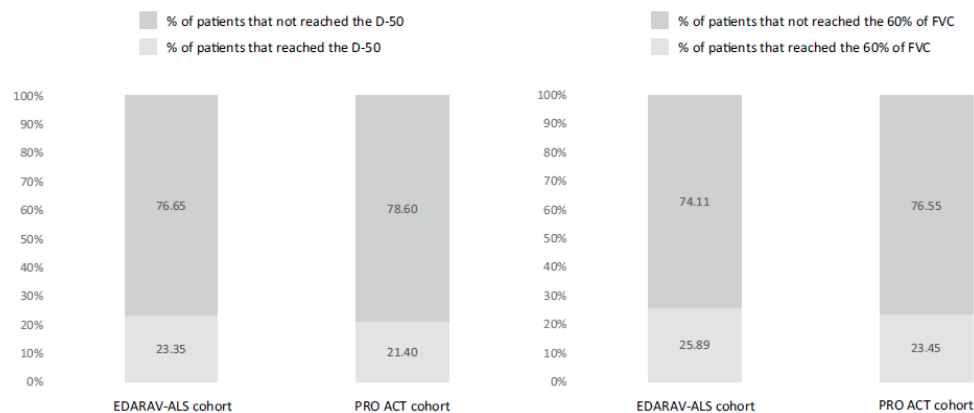
L'attività scientifica propria del GdSMM

- Studio Edarav-ALS (pubblicato)
- Studio 'DAT' (in fase di sottomissione)
- Studio Covid e riluzolo (in corso)
- Studio 'DYALS' (in fase di sottomissione)
- Impact ALS

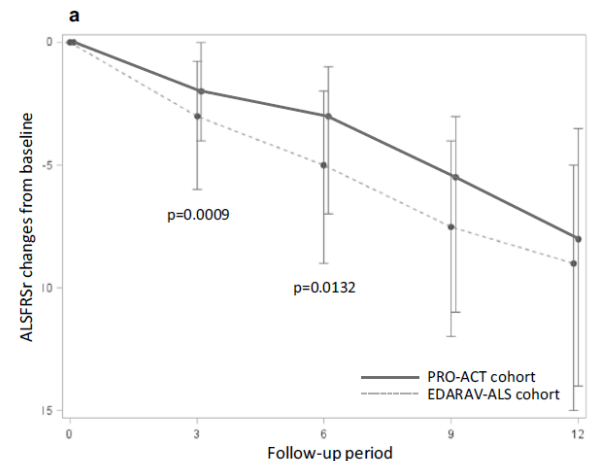
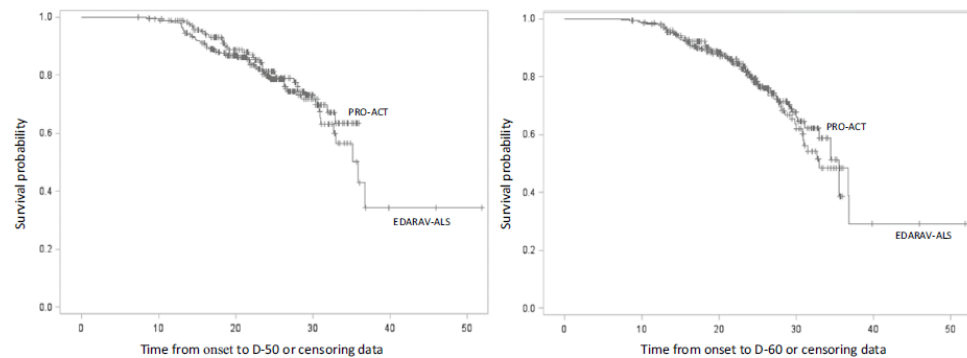


# The Italian multicenter experience with edaravone in amyotrophic lateral sclerosis

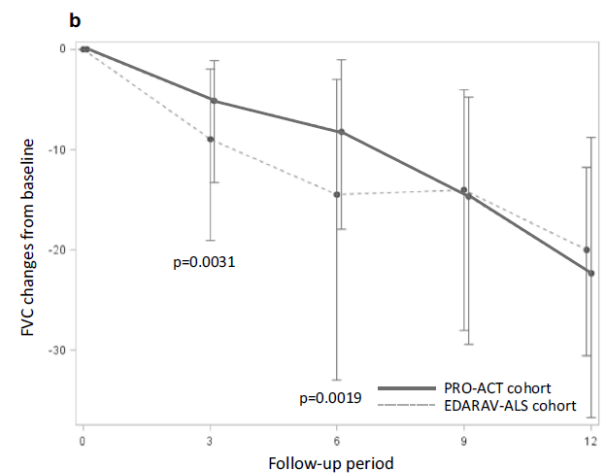
Christian Lunetta<sup>1</sup> · Cristina Moglia<sup>2,3</sup> · Andrea Lizio<sup>1</sup> · Claudia Caponnetto<sup>4</sup> · Raffaele Dubbioso<sup>5</sup> · Fabio Giannini<sup>18</sup> · Sabrina Matà<sup>6</sup> · Letizia Mazzini<sup>7</sup> · Mario Sabatelli<sup>8,9</sup> · Gabriele Siciliano<sup>10</sup> · Isabella Laura Simone<sup>11</sup> · Gianni Sorarù<sup>12</sup> · Antonella Toriello<sup>13</sup> · Francesca Trojsi<sup>14</sup> · Marcella Vedovello<sup>15</sup> · Fabrizio D'Ovidio<sup>2</sup> · Massimo Filippi<sup>16,17</sup> · Andrea Calvo<sup>2,3</sup> · and EDARAVALS Study Group



**Fig. 2** Differences in proportions between the EDARAV-ALS and the PRO-ACT cohorts



EDARAV-ALS cohort	N=197	N=184	N=128	N=74	N=53
PRO-ACT cohort	N=290	N=222	N=215	N=60	N=39



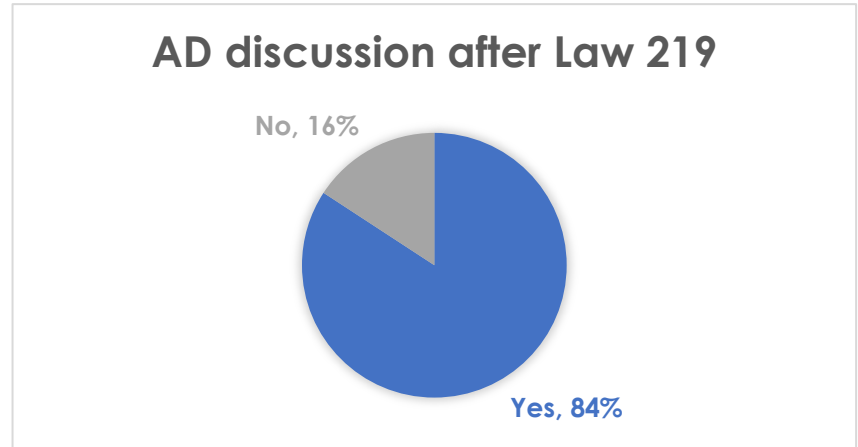
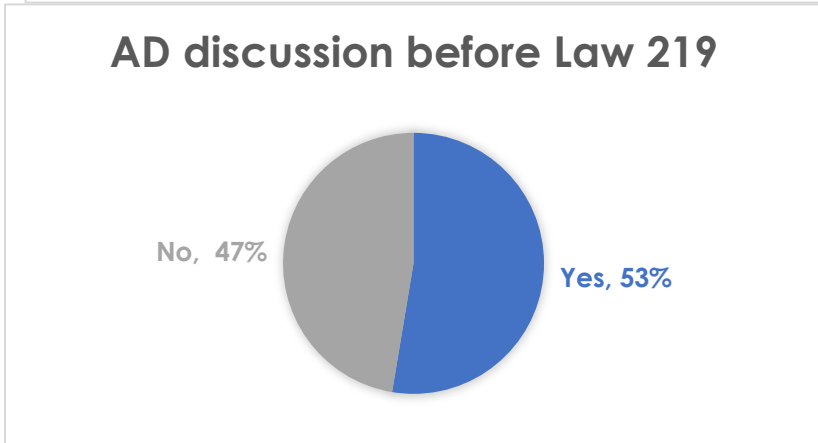
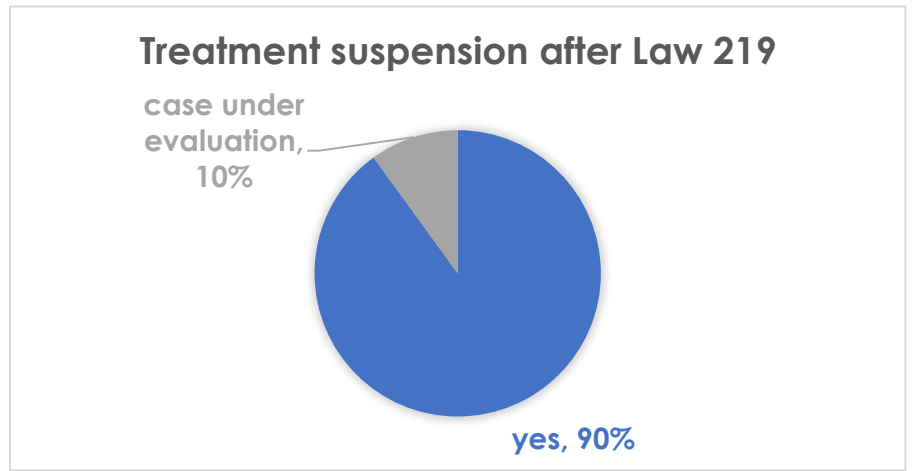
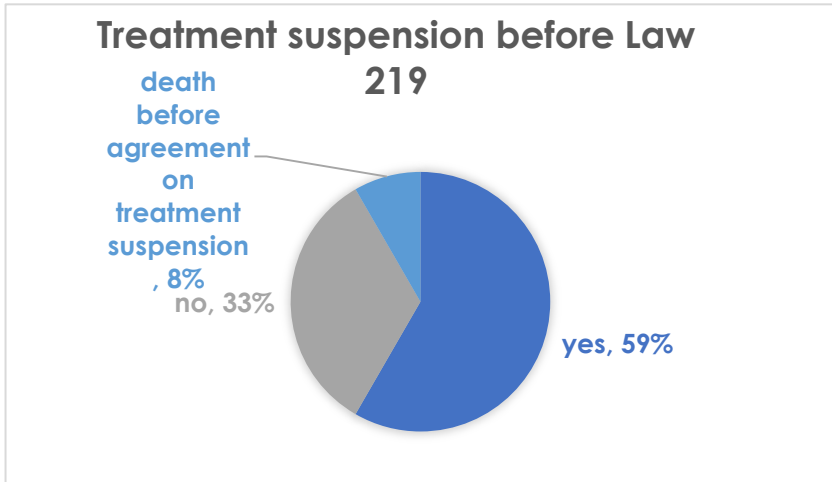
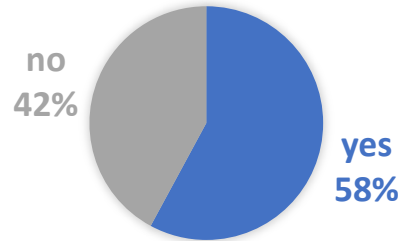
EDARAV-ALS cohort	N=197	N=173	N=122	N=67	N=44
PRO-ACT cohort	N=290	N=214	N=199	N=51	N=39

# Survey rivolta ai medici su *DAT e sospensioni di trattamento in pazienti affetti da SLA*

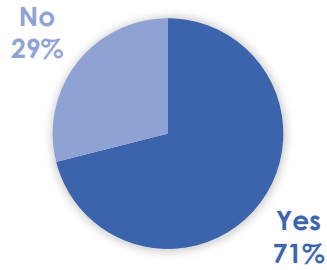


33 centri

# VITAL TREATMENT SUSPENSION REQUEST IN CLINICAL PRACTICE

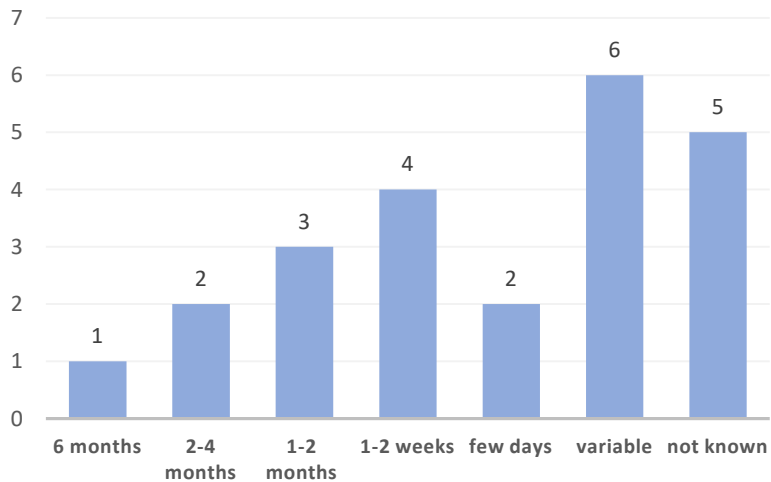


## Multidisciplinary Team

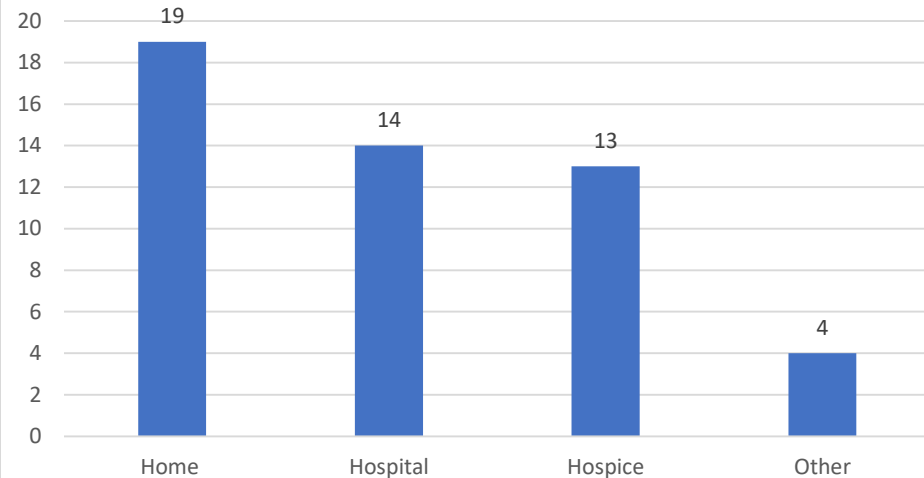


**neurologo - palliativista – psicologo/psichiatra – pneumologo – mmg - medico legale/avvocato dell'a.o.**

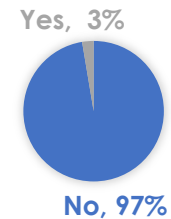
## Timing for treatment suspension



## Setting of treatment suspension



**Have you ever refused or considered inappropriate a treatment suspension request after Law 219**

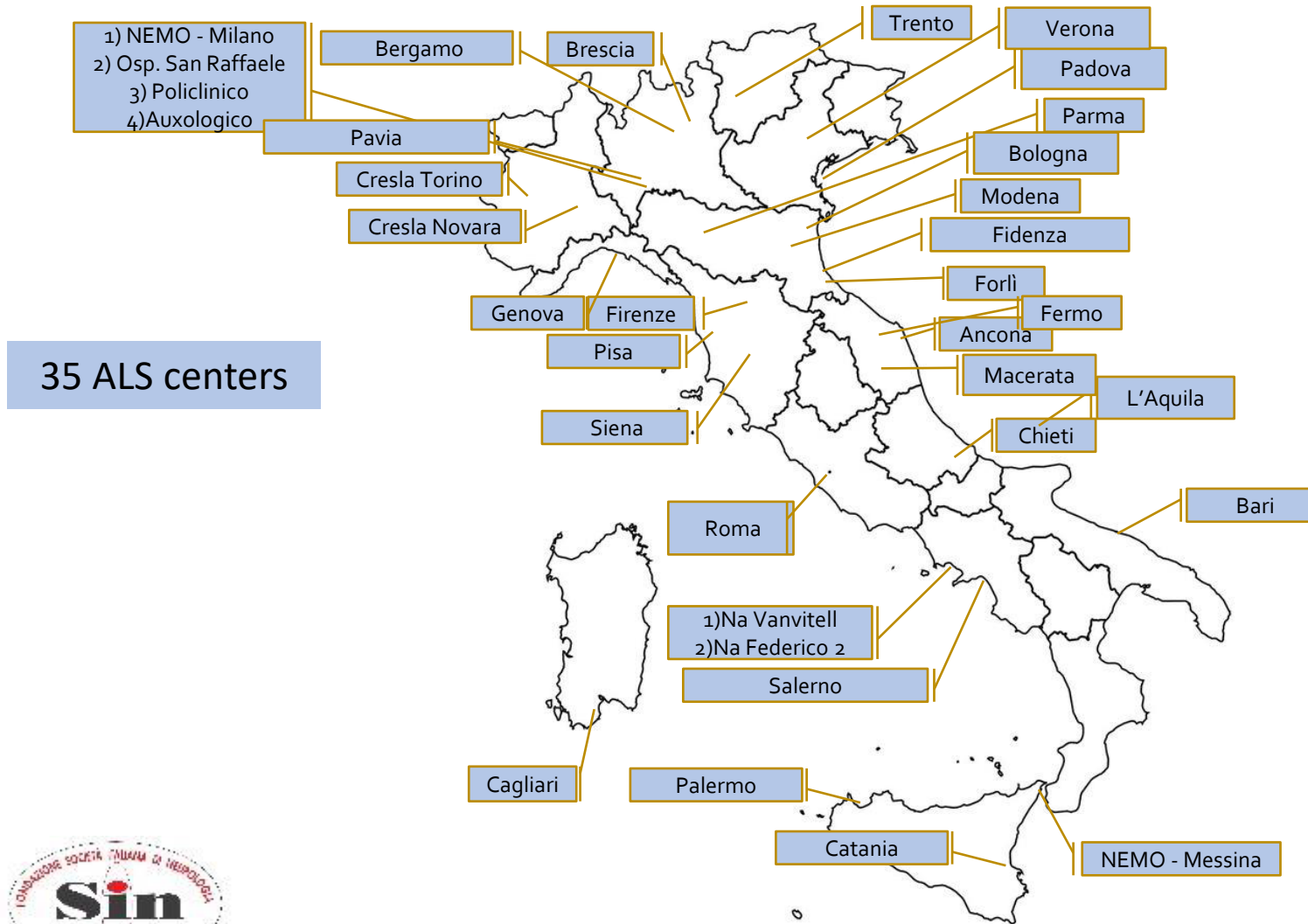


# Covid-19 and riluzole in ALS patients: a multicenter study

Andrea Calvo on behalf of Italian  
Study Group (Società Italiana di  
Neurologia)

University of Turin, Italy on behalf of  
MND Italian Study Group

# Participating Italian ALS Centers

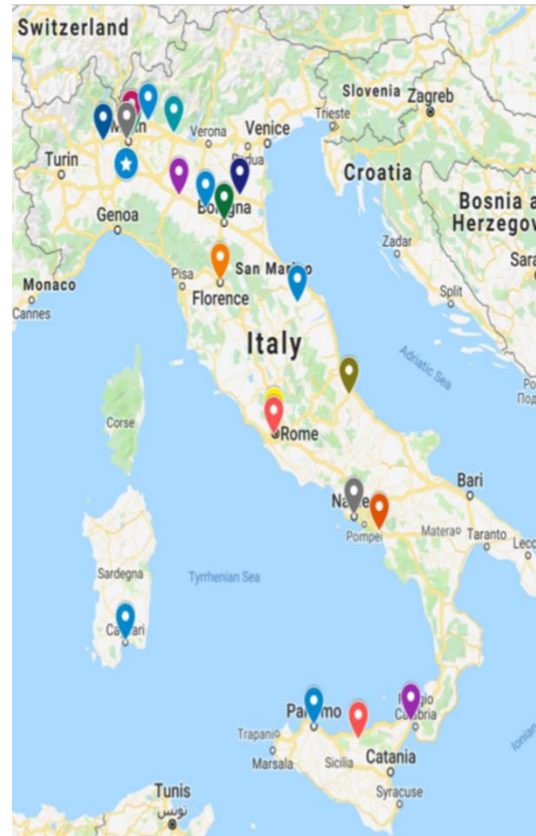
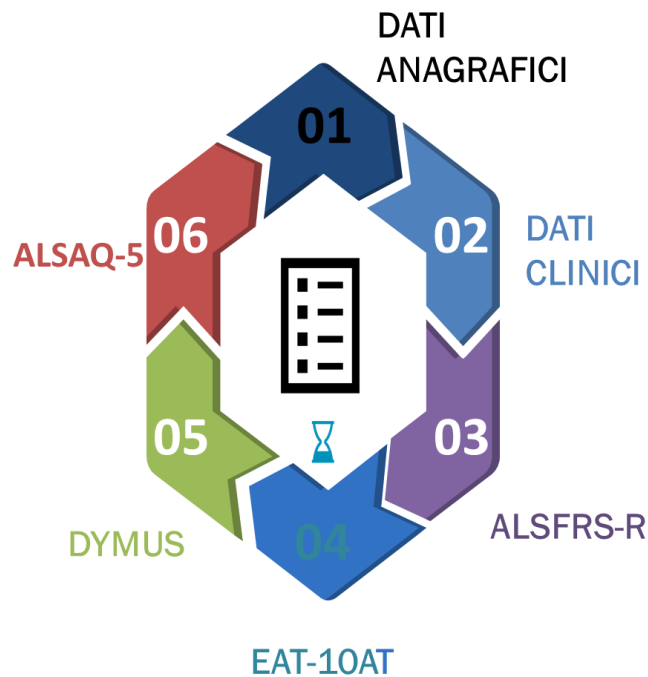


# Preliminary results

	ALS Patients On Riluzole	ALS Patients Not On Riluzole	Relatives/caregiver
<b>Covid-19 Respiratory Illness</b>	26	8	46
<b>Non-Covid-19 Respiratory Illness</b>	136	19	
<b>Covid-19 Asymptomatic</b>	3	0	
<b>Covid-19 with Mild symptoms</b>	12	4	
<b>Death from Covid-19 Respiratory Illness</b>	5	1	
<b>Death from Non-Covid-19 Respiratory Illness</b>	86	15	



# Validation of the DYALS (DYsphagia in Amyotrophic Lateral Sclerosis) questionnaire for the evaluation of dysphagia in ALS patients



- Pavia
- Napoli
- Chieti
- Roma – Sapienza
- Roma – San Camillo
- Bergamo
- Modena
- Monza
- Brescia
- Mistretta
- Milano – Auxologico
- Firenze
- Novara
- Milano – Nemo
- Pisa
- Milano – Maugeri

## 1. Dati clinici e demografici

Patients	n=200
Gender, M/F	115/85 (57.5%/42.5%)
Age at onset, median in years (IQR)	64 (56-72.5)
Time from onset to diagnosis, median in months (IQR)	12 (0-24)
Site of onset, spinal/bulbar	158/42
ALS-FRSr score (total), median (IQR)	35 (28-39)
ALS-FRSr score (items 1-3), median (IQR)	11 (9-12)
ALS-FRSr score (items 4-5), median (IQR)	6 (3-7)
ALS-FRSr score (items 6-7), median (IQR)	5 (3-7)
ALS-FRSr score (items 8-9), median (IQR)	3 (2-5)
ALS-FRSr score (items 10-12), median (IQR)	12 (10-12)

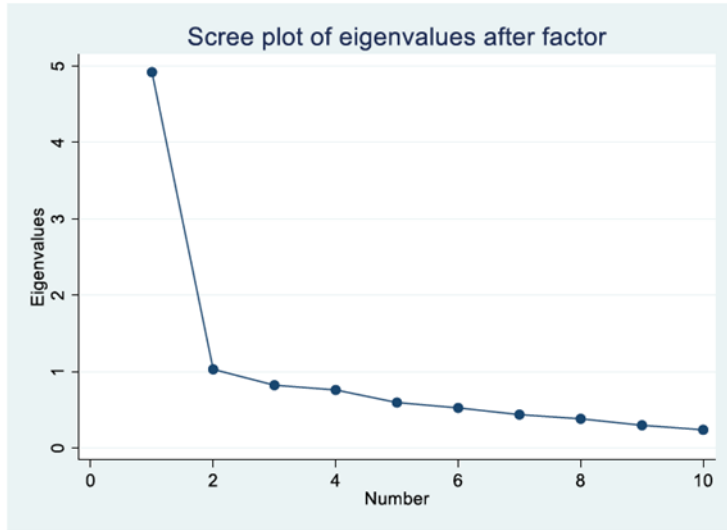
## 2. Mediana punteggio DYALS per tipo esordio

	Bulbare		Spinale		
Score DYALS	Mediana	IQR	Mediana	IQR	p-value
Wilcoxon rank-sum test (Mann-Whitney test)	6	4.5-9	1	0-5	<0.0001

## 3. Punteggio DYALS globale

	Intero campione		Esordio bulbare		Esordio spinale	
Punteggio DYALS	N°	%	N°	%	N°	%
≥ 3	97	48.73%	37	90%	60	38.22%
< 3	103	51.27%	5	10%	98	61.78%

#### 4. Studio di dimensionalità



#### 5. Consistenza interna

Items	Alpha
D1	0.87
D2	0.87
D3	0.88
D4	0.88
D5	0.87
D6	0.87
D7	0.87
D8	0.86
D9	0.86
D10	0.88
TOTALE	0.88

#### 6. Validazione esterna DYALS-EAT10

	Rho Spearman	di	p-value
DYALS	0.9		< 0.0001
Sottoscala solidi	0.95		
Sottoscala liquidi	0.91		

**Paper entro fine anno!**

Il GdS malattie del motoneurone  
ha aderito al progetto Impact-ALS

I casi italiani nella tabella sono tutti  
derivanti dai Centri aderenti al GdS



## Lei è un/a paziente con SLA/MND o una persona che lo/a assiste?

Faccia clic qui per condividere le Sue esperienze riguardo il sondaggio europeo sulla  
SLA per aiutare a guidare lo sviluppo di nuovi farmaci e servizi per la SLA



Nel tentativo di includere il Suo punto di vista per aiutare a guidare lo sviluppo di nuovi farmaci e servizi per la SLA, stiamo conducendo un sondaggio dei/delle pazienti con SLA e delle persone che se ne prendono cura. Quest'iniziativa, intitolata IMPACT-ALS (sperimentazione e misurazione delle tendenze dei/delle pazienti e delle persone che se ne prendono cura riguardo alla SLA), una collaborazione di ricerca tra industria, medici della SLA europei ed enti di beneficenza relativi alla SLA

Language	Total accepted consent statement	Total response (Are you a person living with ALS/MND or caregiver - Q2)	Caregiver	Bereaved caregiver	A person with ALS/MND/Assisting a person
German	81	67	20	11	35
English	226	213	62	37	112
Spanish	230	211	56	91	64
French	214	201	44	37	119
French - BE	2	2	1	0	1
Italian	646	607	219	20	365
Dutch - NL	186	175	31	6	137
Dutch - BE	10	10	1	0	9
Swedish	64	60	16	16	28
<b>Total</b>	<b>1659</b>	<b>1546</b>	<b>450</b>	<b>218</b>	<b>870</b>