

Clinical characteristics and demographics	Patient Groups						
	Non-genetically confirmed patients	All genetically confirmed patients	All genetically confirmed LGMDR9 patients	Homozygous common in LGMDR9	Heterozygous common in LGMDR9	Homozygous unique in LGMDR9	Heterozygous unique in LGMDR9
Patients (n)	343	320	-	-	-	-	-
Sex (f/m, n)	183/160	177/143	-	-	-	-	-
LGMD R9 patients (n)	-	-	305	207	87	3	8
Sex (f/m, n)	-	-	168/137	117/90	45/42	1/2	5/3
<b>Diagnosis</b>							
Mean age of genetically confirmed diagnosis (years $\pm$ SD, n) (at time of diagnosis)	-	29.9 $\pm$ 17.5 (259) F(141): 30.8 $\pm$ 16.5 M(118): 29.0 $\pm$ 18.6	30.1 $\pm$ 17.3 (251) F(138): 31.1 $\pm$ 16.4 M(113): 28.8 $\pm$ 18.3	34.8 $\pm$ 15.9 (164) F(90): 35.1 $\pm$ 15.2 M(74): 34.5 $\pm$ 16.8	20.7 $\pm$ 16.5 (76) F(42): 23.2 $\pm$ 16.2 M(34): 17.5 $\pm$ 16.5	19.2 $\pm$ 7.4 (3) F(1): 17.6 M(2): 20.0 $\pm$ 10.3	26.1 $\pm$ 16.6 (8) F(5): 29.3 $\pm$ 17.4 M(3): 20.7 $\pm$ 17.0
<b>Disease onset</b>							
Mean age of symptom onset (years $\pm$ SD, n)	9.0 $\pm$ 6.4 (4) F(1): 7.0 M(3): 9.7 $\pm$ 7.6	14.8 $\pm$ 12.3 (155) F(88): 14.2 $\pm$ 11.0 M(67): 15.7 $\pm$ 13.9	15.1 $\pm$ 12.3 (152) F(86): 14.5 $\pm$ 10.9 M(66): 15.9 $\pm$ 13.9	19.0 $\pm$ 12.4 (102) F(61): 17.6 $\pm$ 10.6 M(41): 21.0 $\pm$ 14.5	6.8 $\pm$ 7.3 (44) F(22): 6.4 $\pm$ 7.2 M(22): 7.2 $\pm$ 7.5	5.8 $\pm$ 0.4 (2) F(1): 5.5 M(1): 6.0	12.0 $\pm$ 9.3 (4) F(2): 12.5 $\pm$ 10.6 M(2): 11.5 $\pm$ 12.0
<b>Presenting symptoms (occurring in &gt; 30% of all patients)</b>							
Weakness in lower limbs (f/m, n)	3/3 (6)	64/45 (109)	63/44 (107)	47/28 (75)	16/15 (31)	0	0/1 (1)
Weakness in lower limbs, mean age of onset (years $\pm$ SD, n)	9.7 $\pm$ 7.6 (3) F(0) M(3): 9.7 $\pm$ 7.6	16.9 $\pm$ 12.8 (103) F(60): 16.4 $\pm$ 12.8 M(43): 17.6 $\pm$ 14.6	17.2 $\pm$ 12.8 (101) F(59): 16.6 $\pm$ 12.8 M(42): 18.0 $\pm$ 14.5	21.2 $\pm$ 12.3 (71) F(45): 19.4 $\pm$ 11.0 M(26): 24.3 $\pm$ 14.1	7.3 $\pm$ 7.8 (29) F(14): 7.8 $\pm$ 8.6 M(15): 6.8 $\pm$ 7.2	0 F(0) M(0)	20.0 (1) F(0) M(1): 20.0
Proximal weakness (f/m, n)	2/2 (4)	40/31 (71)	39/30 (69)	30/17 (47)	7/10 (17)	1/1 (2)	1/2 (3)
Proximal weakness, mean age of onset (years $\pm$ SD, n)	10.5 $\pm$ 10.6 (2) F(0) M(2): 10.5 $\pm$ 10.6	17.5 $\pm$ 12.8 (65) F(35): 18.0 $\pm$ 11.6 M(30): 17.0 $\pm$ 14.2	18.1 $\pm$ 12.6 (63) F(34): 18.4 $\pm$ 11.4 M(29): 17.6 $\pm$ 14.1	22.3 $\pm$ 12.2 (43) F(27): 21.5 $\pm$ 10.8 M(16): 23.7 $\pm$ 14.5	9.3 $\pm$ 8.4 (15) F(5): 7.4 $\pm$ 3.5 M(10): 10.3 $\pm$ 10.0	5.8 $\pm$ 0.4 (2) F(1): 6.0 M(1): 6.0	9.3 $\pm$ 9.3 (3) F(1): 5.0 M(2): 11.5 $\pm$ 12.0
Hyperckemia (f/m, n)	4/1 (5)	30/23 (53)	29/23 (52)	17/12 (29)	9/10 (19)	1/1 (2)	2/0 (2)
Hyperckemia, mean age of onset (years $\pm$ SD, n)	12.5 $\pm$ 7.8 (2) F(1): 7.0 M(1): 18.0	10.8 $\pm$ 8.8 (50) F(28): 11.3 $\pm$ 7.6 M(22): 10.2 $\pm$ 10.3	11.0 $\pm$ 8.8 (49) F(27): 11.7 $\pm$ 7.6 M(22): 10.2 $\pm$ 10.3	14.6 $\pm$ 9.2 (27) F(16): 15.0 $\pm$ 7.2 M(11): 13.9 $\pm$ 11.9	6.1 $\pm$ 5.9 (18) F(8): 5.5 $\pm$ 3.5 M(10): 6.6 $\pm$ 7.4	5.8 $\pm$ 0.4 (2) F(1): 5.5 M(1): 6.0	12.5 $\pm$ 10.6 (2) F(2): 12.5 $\pm$ 10.6 M(0)
<b>Current motor function</b>							
Ambulant (+/- support) (f/m, n)	129/105 (234)	128/111 (239)	123/106 (229)	99/73 (169)	23/30 (53)	1/2 (3)	3/1 (4)
Mean age of patients able to climb stairs (+/- support) (years $\pm$ SD, n)	36.8 $\pm$ 14.5 (78) F(40): 36.0 $\pm$ 13.2 M(38): 37.7 $\pm$ 15.8	39.1 $\pm$ 15.0 (80) F(45): 39.8 $\pm$ 17.5 M(35): 38.3 $\pm$ 13.8	39.3 $\pm$ 16.3 (77) F(43): 40.1 $\pm$ 16.6 M(34): 38.2 $\pm$ 16.2	43.5 $\pm$ 14.6 (59) F(37): 41.2 $\pm$ 16.1 M(22): 47.3 $\pm$ 10.9	25.5 $\pm$ 16.9 (15) F(5): 35.1 $\pm$ 21.5 M(10): 20.6 $\pm$ 9.7	25.0 $\pm$ 6.0 (3) F(1): 24.3 M(2): 25.4 $\pm$ 8.4	0 F(0) M(0)
Mean age of patients able to walk (+/- support) (years $\pm$ SD, n)	38.3 $\pm$ 16.1 (115) F(68): 38.0 $\pm$ 16.0 M(47): 38.7 $\pm$ 16.5	44.9 $\pm$ 15.4 (116) F(68): 44.9 $\pm$ 14.1 M(48): 45.0 $\pm$ 17.3	44.9 $\pm$ 15.1 (110) F(66): 44.6 $\pm$ 14.2 M(44): 45.3 $\pm$ 16.7	47.0 $\pm$ 13.4 (82) F(50): 45.5 $\pm$ 13.1 M(32): 49.5 $\pm$ 13.8	37.4 $\pm$ 18.7 (25) F(14): 40.3 $\pm$ 18.0 M(11): 33.7 $\pm$ 19.8	0 F(0) M(0)	49.5 $\pm$ 8.0 (3) F(2): 53.8 $\pm$ 4.3 M(1): 40.9
Non-ambulant (f/m, n)	43/38 (81)	47/31 (78)	44/31 (75)	21/17 (38)	21/12 (33)	0	2/2 (4)
Wheelchair use, part-time (f/m, n)	42/27 (69)	46/32 (78)	46/31 (77)	37/17 (54)	8/13 (21)	0	1/1 (2)
Mean age of part-time wheelchair users (years $\pm$ SD, n)	37.6 $\pm$ 16.5 (69) F(42): 38.5 $\pm$ 16.7 M(27): 36.2 $\pm$ 16.4	39.9 $\pm$ 18.0 (78) F(46): 41.4 $\pm$ 16.3 M(32): 37.9 $\pm$ 19.7	40.3 $\pm$ 17.6 (77) F(46): 41.4 $\pm$ 16.3 M(31): 38.7 $\pm$ 19.5	45.8 $\pm$ 15.8 (54) F(37): 43.6 $\pm$ 15.2 M(17): 50.5 $\pm$ 16.4	25.4 $\pm$ 13.6 (21) F(8): 28.9 $\pm$ 16.6 M(13): 23.2 $\pm$ 11.6	0 F(0) M(0)	48.9 $\pm$ 11.3 (2) F(1): 56.8 M(1): 40.9
Wheelchair use, full-time (f/m, n)	49/35 (84)	52/28 (80)	49/28 (77)	23/15 (38)	24/11 (35)	0	2/2 (4)
Mean age of full-time wheelchair users (years $\pm$ SD, n)	40.2 $\pm$ 18.1 (84) F(49): 37.2 $\pm$ 15.0 M(35): 44.2 $\pm$ 21.3	42.1 $\pm$ 16.4 (80) F(52): 40.9 $\pm$ 16.2 M(28): 44.1 $\pm$ 16.8	42.5 $\pm$ 16.1 (77) F(49): 41.5 $\pm$ 15.9 M(28): 44.1 $\pm$ 16.8	53.2 $\pm$ 12.7 (38) F(23): 52.4 $\pm$ 12.9 M(15): 54.3 $\pm$ 12.6	32.6 $\pm$ 12.0 (35) F(24): 31.5 $\pm$ 11.8 M(11): 34.8 $\pm$ 12.6	0 F(0) M(0)	27.4 $\pm$ 10.2 (4) F(2): 36.0 $\pm$ 3.9 M(2): 18.9 $\pm$ 2.2
<b>Ventilation</b>							
Non-invasive (f/m, n)	28/16 (44)	32/17 (49)	30/16 (46)	20/11 (31)	8/4 (12)	0	2/1 (3)
Mean age of starting non-invasive ventilation (years $\pm$ SD, n)	35.3 $\pm$ 14.0 (39) F(24): 34.4 $\pm$ 12.9 M(15): 36.7 $\pm$ 15.9	39.4 $\pm$ 15.9 (42) F(28): 39.9 $\pm$ 15.0 M(14): 38.4 $\pm$ 18.2	40.8 $\pm$ 15.0 (39) F(26): 40.6 $\pm$ 14.9 M(13): 41.1 $\pm$ 15.7	46.6 $\pm$ 13.7 (24) F(16): 45.5 $\pm$ 15.4 M(8): 48.8 $\pm$ 10.1	32.7 $\pm$ 13.2 (12) F(8): 33.3 $\pm$ 11.9 M(4): 31.5 $\pm$ 17.3	0 F(0) M(0)	26.6 $\pm$ 7.0 (3) F(2): 30.5 $\pm$ 2.1 M(1): 18.8
Invasive (f/m, n)	3/1 (4)	7/2 (9)	7/2 (9)	3/1 (4)	4/1 (5)	0	0
Mean age of starting invasive ventilation (years $\pm$ SD, n)	27.5 $\pm$ 12.6 (4) F(3): 23.1 $\pm$ 11.0 M(1): 40.8	43.1 $\pm$ 10.3 (6) F(5): 43.9 $\pm$ 11.3 M(1): 39.0	43.1 $\pm$ 10.3 (6) F(5): 43.9 $\pm$ 11.3 M(1): 39.0	62.0 (1) F(1): 62.0 M(0)	39.3 $\pm$ 5.0 (5) F(4): 39.4 $\pm$ 5.7 M(1): 39.0	0 F(0) M(0)	0 F(0) M(0)