

Supplemental Table 1. Overall Prevalence, Average Life Impact Scores, Population Impact Scores (n=124)

	Prevalence (%)	Average Life Impact	Population Impact
Problems with urinary or bowel control	39	2.37	0.92
Gastrointestinal issues	75	1.90	1.43
Communication issues	70	1.87	1.32
Impaired sleep or daytime Sleepiness	69	1.81	1.25
Fatigue	74	1.80	1.34
Limitations with mobility and ambulation	64	1.69	1.07
Myotonia	59	1.69	1.00
Inability to do activities	68	1.68	1.14
Difficulty thinking	62	1.66	1.02
Hip, thigh, or knee weakness	52	1.62	0.84
Problems with hands or fingers	79	1.56	1.24
Problems with vision, hearing, or smell	57	1.49	0.85
Problems with shoulders or arms	52	1.40	0.72
Problems with choking or swallowing	41	1.39	0.58
Emotional Issues	64	1.36	0.86
Decreased social situation satisfaction	44	1.31	0.58
Changed body image	53	1.28	0.69
Pain	64	1.25	0.79

	Prevalence (%)	Average Life Impact	Population Impact
Decreased social situation performance	45	1.19	0.53
Back, chest, or abdomen weakness	51	1.15	0.59

Supplemental Table 2. Prevalence by Age Groups

	Prevalence (%)					<i>p</i> value
	5-7 n=11	8-11 n=12	12-17 n=33	18-28 n=39	28+ n=29	
Limitations with mobility and ambulation	73	50	60	55	79	0.003
Hip, thigh, or knee weakness	45	50	50	47	64	0.249
Back, chest, or abdomen weakness	18	33	53	61	61	0.517
Problems with hands or fingers	55	67	62	95	89	0.178
Problems with shoulders or arms	18	58	47	51	71	0.465
Inability to do activities	64	55	62	79	79	0.702
Myotonia	18	33	41	79	79	0.312
Gastrointestinal issues	64	83	77	73	71	0.050
Problems with urinary or bowel control	64	58	40	28	30	0.181
Problems with choking or swallowing	18	58	53	68	63	0.374
Emotional Issues	36	83	77	56	63	0.114

	5-7 n=11	8-11 n=12	12-17 n=33	18-28 n=39	28+ n=29	<i>p</i> value
Changed body image	27	67	59	49	57	0.220
Difficulty thinking	64	83	79	53	43	0.136
Decreased social situation satisfaction	18	55	21	60	50	0.101
Decreased social situation performance	18	33	31	57	56	0.087
Impaired sleep or daytime sleepiness	9	58	69	86	74	0.168
Fatigue	64	75	64	89	79	0.077
Pain	27	58	77	63	64	0.215
Problems with vision, hearing, or smell	18	42	31	53	50	0.464
Communication issues	82	67	86	61	61	0.044

Supplemental Table 3. Prevalence by CTG Repeat Length

	Prevalence (%)				<i>p</i> value
	0-500 n=19	501-1000 n=38	1001- 1500 n=8	1501+ n=6	
Limitations with mobility and ambulation	47	71	50	100	0.120
Hip, thigh, or knee weakness	26	53	50	100	0.085
Back, chest, or abdomen weakness	21	58	38	67	0.751
Problems with hands or fingers	53	84	75	83	0.049
Problems with shoulders or arms	37	47	38	67	0.396
Inability to do activities	53	63	100	100	0.061
Myotonia	47	70	43	33	0.655
Gastrointestinal issues	68	76	75	100	0.070
Problems with urinary or bowel control	21	39	63	100	0.065
Problems with choking or swallowing	53	53	25	67	0.200
Emotional Issues	56	68	50	67	0.371
Changed body image	68	55	50	50	0.920
Difficulty thinking	58	68	100	83	0.634
Decreased social situation satisfaction	50	37	38	60	0.614
Decreased social situation performance	58	39	38	50	0.494
Impaired sleep or daytime sleepiness	68	68	38	50	0.187

	0-500 n=19	501-1000 n=38	1001- 1500 n=8	1501+ n=6	<i>p</i> value
Fatigue	78	82	75	67	0.909
Pain	53	63	63	83	0.574
Problems with vision, hearing, or smell	47	39	38	83	0.165
Communication issues	74	73	100	100	0.004

Supplemental Table 4. Prevalence by CTG Repeat Length

	Prevalence (%)				<i>p</i> value
	0-500 n=19	501-1000 n=38	1001- 1500 n=8	1501+ n=6	
Limitations with mobility and ambulation	47	71	50	100	0.120
Hip, thigh, or knee weakness	26	53	50	100	0.085
Back, chest, or abdomen weakness	21	58	38	67	0.751
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Fatigue	78	82	75	67	0.909
Pain	53	63	63	83	0.574
Problems with vision, hearing, or smell	47	39	38	83	0.165
Communication issues	74	73	100	100	0.004

Supplemental Table 5. Average Life Impact by CTG Repeat Length

	Average Life Impact				<i>p</i> -value
	0-500 n=19	501- 1000 n=38	1000- 1500 n=8	1501+ n=6	
Limitations with mobility and ambulation	0.74	0.90	1.13	2.83	0.062
Hip, thigh, or knee weakness	0.37	0.84	0.88	2.00	0.055
Back, chest, or abdomen weakness	0.21	0.58	0.25	0.67	0.251
Problems with hands or fingers	0.79	1.40	1.00	1.33	0.043
Problems with shoulders or arms	0.37	0.71	0.00	1.50	0.184
Inability to do activities	0.68	1.08	1.75	2.80	0.029
Myotonia	0.47	1.27	0.29	0.83	0.322
Gastrointestinal issues	1.16	1.53	1.37	2.33	0.090
Problems with urinary or bowel control	0.37	0.92	1.88	3.00	0.025
Problems with choking or swallowing	0.53	1.08	0.00	1.33	0.060

Emotional Issues	0.89	0.89	0.75	1.67	0.682
Changed body image	0.37	0.71	1.13	1.17	0.505
Difficulty thinking	0.90	1.03	1.75	2.67	0.450
Decreased social situation satisfaction	1.00	0.45	0.12	0.80	0.864
Decreased social situation performance	0.84	0.37	0.12	1.00	0.971
Impaired sleep or daytime Sleepiness	1.16	1.37	0.75	0.67	0.050
Fatigue	1.28	1.53	1.63	1.50	0.776
	0-500	501-1000	1000-1500	1501+	<i>p</i> -value
	n=19	n=38	n=8	n=6	
Pain	0.63	0.92	0.50	1.33	0.257
Problems with vision, hearing, or smell	0.58	0.39	1.13	1.33	0.137
Communication issues	0.89	1.68	2.00	2.83	0.006



Supplemental Table 6. Prevalence by Age of Disease Onset

	Prevalence (%)		<i>p</i> value
	<1 year age n=54	>1 year age n=67	
Limitations with mobility and ambulation	69	62	0.568
Hip, thigh, or knee weakness	60	48	0.274
Back, chest, or abdomen weakness	54	51	0.856
Problems with hands or fingers	80	82	1.00
Problems with shoulders or arms	51	54	0.855
Inability to do activities	69	65	0.699
Myotonia	43	74	0.001
Gastrointestinal issues	81	70	0.207
Problems with urinary or bowel control	44	30	0.181
Problems with choking or swallowing	54	60	0.581
Emotional Issues	68	60	0.445
Changed body image	45	58	0.201
Difficulty thinking	71	51	0.026
Decreased social situation satisfaction	35	49	0.191
Decreased social situation performance	36	50	0.141
Impaired sleep or daytime sleepiness	62	75	0.167
	<1 year age	>1 year age	<i>p</i> value

	n=54	n=67	
Fatigue	77	75	0.832
Pain	63	65	1.00
Problems with vision, hearing, or smell	38	43	0.709
Communication issues	77	61	0.077

Supplemental Table 7. Average Life Impact by Age of Disease Onset

	Average Life Impact		<i>p</i> value
	<1 year age n=54	>1 year age n=69	
Limitations with mobility and ambulation	1.97	1.33	0.053
Hip, thigh, or knee weakness	1.69	1.48	0.771
Back, chest, or abdomen weakness	1.41	0.94	0.095
Problems with hands or fingers	1.58	1.50	0.825
Problems with shoulders or arms	1.30	1.49	0.550
Inability to do activities	2.05	1.38	0.053
Myotonia	1.54	1.69	0.451
Gastrointestinal issues	1.76	1.83	0.804

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Problems with urinary or bowel control	2.91	1.81	0.016
Problems with choking or swallowing	1.60	1.34	0.618
Emotional Issues	1.47	1.23	0.376
Changed body image	1.70	1.03	0.035
Difficulty thinking	1.92	1.40	0.101
Decreased social situation satisfaction	1.50	1.21	0.689
Decreased social situation performance	1.32	1.12	0.634
Impaired sleep or daytime sleepiness	1.72	1.86	0.644

	<1 year age n=54	>1 year age n=67	<i>p</i> value
Fatigue	1.80	1.92	0.590
Pain	1.18	1.32	0.359
Problems with vision, hearing, or smell	1.60	1.27	0.297
Communication issues	2.32	1.38	0.001