

ADDITIONAL FILE 3

Distribution of Impact on Quality of Life by Disease Severity

	Patients, n (%)							
	Mild		Moderate		Severe		Overall	
	BL	Wk4	BL	Wk4	BL	Wk4	BL	Wk4
	N=9	N=9	N=10	N=9	N=11	N=11	N=30	N=29
QOLEB								
Very mild (0-4)	1 (11.1)	1 (11.1)	0	0	0	0	1 (3.3)	1 (3.4)
Mild (5-9)	1 (11.1)	2 (22.2)	4 (40.0)	3 (33.3)	0	0	5 (16.7)	5 (17.2)
Moderate (10-19)	6 (66.7)	5 (55.6)	2 (20.0)	3 (33.3)	2 (18.2)	4 (36.4)	10 (33.3)	12 (41.4)
Severe (20-34)	1 (11.1)	1 (11.1)	4 (40.0)	3 (33.3)	9 (81.8)	7 (63.6)	14 (46.7)	11 (37.9)
DLQI	N=3	N=3	N=7	N=6	N=5	N=5	N=15	N=14
No effect (0-1)	0	1 (33.3)	0	0	0	0	0	1 (6.7)
Small effect (2-5)	1 (33.3)	0	4 (57.1)	3 (42.9)	1 (20.0)	0	6 (40.0)	3 (20.0)
Moderate effect (6-10)	1 (33.3)	1 (33.3)	1 (14.3)	2 (28.6)	2 (40.0)	2 (40.0)	4 (26.7)	5 (33.3)
Very large effect (11-20)	1 (33.3)	1 (33.3)	1 (14.3)	1 (14.3)	2 (40.0)	3 (60.0)	4 (26.7)	5 (33.3)
Extremely large effect (21-30)	0	0	1 (14.3)	0	0	0	1 (6.7)	0
CDLQI	N=5	N=5	N=2	N=2	N=6	N=6	N=13	N=13
No effect (0-1)	0	0	0	0	0	0	0	0
Small effect (2-6)	4 (80.0)	2 (40.0)	0	0	1 (16.7)	1 (16.7)	5 (38.5)	3 (23.1)
Moderate effect (7-12)	1 (20.0)	2 (40.0)	1 (50.0)	1 (50.0)	1 (16.7)	4 (66.7)	3 (23.1)	7 (53.8)
Very large effect (13-18)	0	1 (20.0)	1 (50.0)	1 (50.0)	3 (50.0)	0	4 (30.8)	2 (15.4)
Extremely large effect (19-30)	0	0	0	0	1 (16.7)	1 (16.7)	1 (7.7)	1 (7.7)

DLQI was completed by patients >16 years. CDLQI was completed by patients 4-16 years.

BL, baseline; CLDQI, Children's DLQI; DLQI, Dermatology Life Quality Index; QOLEB, Quality of Life in Epidermolysis Bullosa; wk, week.