

Table SI. Patient characteristics of the study population

	Participants n=55	Drop outs n=48
Age, years, mean $\pm$ SD (range)	47.6 $\pm$ 17.1 (19–85)	36.9 $\pm$ 12.3 (18–67)
Gender, n (%)		
Male	28 (51)	17 (35)
Female	27 (49)	31 (65)
Epidermolysis bullosa (EB) subtype, n (%)		
EBS	29 (53)	20 (42)
EBS-loc	20 (36)	12 (25)
EBS-gen-nonDM	2 (4)	2 (4)
EBS-DM	4 (7)	2 (4)
EBS-AR	3 (5)	2 (4)
EBS-MP	–	1 (2)
EBS-MD	–	1 (2)
JEB	8 (15)	8 (17)
JEB-nH loc	4 (7)	2 (4)
JEB-nH gen	4 (7)	4 (8)
JEB-lo	–	2 (4)
DEB	18 (33)	20 (42)
DDEB	13 (24)	14 (29)
DDEB-pt	3 (5)	–
DDEB-ac	3 (5)	7 (15)
DDEB-gen	7 (13)	7 (15)
RDEB	5 (9)	6 (13)
RDEB-I	2 (4)	1 (2)
RDEB-O	2 (4)	4 (8)
RDEB-sev gen	1 (2)	1 (2)

EBS: epidermolysis bullosa simplex; EBS-loc: EBS localised; EBS-gen-nonDM: EBS other generalised; EBS-DM: EBS Dowling-Meara; EBS-AR: EBS autosomal recessive; EBS-MP: EBS with mottled pigmentation; EBS-MD: EBS with muscular dystrophy; JEB: junctional epidermolysis bullosa; JEB-nH loc: JEB non-Herlitz localised; JEB-nH gen: JEB non-Herlitz generalised; JEB-lo: JEB of late onset; DEB: dystrophic epidermolysis bullosa; DDEB: dominant DEB; DDEB-pt: DDEB pretibial; DDEB-ac: DDEB acral; DDEB-gen: DDEB generalised; RDEB: recessive DEB; RDEB-O: RDEB generalised other; RDEB-I: RDEB inverse; RDEB-sev gen: RDEB severe generalised.