

Table SI. Additional unmet needs in pemphigoid diseases by patients, clinicians and researchers

Additional unmet needs	Times mentioned, <i>n</i>
<i>Categorized additional unmet needs in pemphigoid diseases among patients</i>	
Need for more (public) information	9
Need for more awareness amongst doctors/medical staff	7
Need for better disease knowledge by doctors	7
Need for better healthcare organization	5
Need for attention and care for intense itching post-BP (after blistering stage; after remission)	4
Need for better medicine	4
Need for more information/guidance	4
Need for research	4
Need for more local support groups	2
Need for guidance of frail elderly population (caregiver to help with nutrition/self-care)	1
<i>Categorized additional unmet needs in pemphigoid diseases among clinicians</i>	
Need for better therapies	11
Need for resolving issues with coverage of medication by insurance companies	4
Need for better diagnostics	3
Need for a centralized national serum database/DNA bank and need for registries	2
Need for nosology for linear IgA disease and pemphigoid (not a synonym for BP)	1
Need for guideline for diagnosis/treatment of MMP and treatment of BP	1
Need for better education of patients on their disease	1
Need for transfer of knowledge to GPs on the non-bullous stages of disease	1
Need for access to nursing support in outpatient setting	1
<i>Categorized additional unmet needs in pemphigoid diseases among researchers</i>	
Need for animal/ex vivo model of human pemphigoid	2
Need for research on pathogenesis of pemphigoid diseases	2
Need for research on brain and skin associations in BP	2
Need for research; why is BP a self-limiting disorder	1
Need for research on cytokine network in amplifying blistering development	1

BP: bullous pemphigoid; RCT: randomized controlled trial; DNA: deoxyribonucleic acid; GP: general practitioner; MMP: mucous membrane pemphigoid.

Table SII. Satisfaction of patients (n = 71) with patient care during the diagnostic process, and their current patient care

Patients satisfied with diagnostic process, n = 36 (51%)		Patients unsatisfied with diagnostic process, n = 35 (49%)	
Reasons categorized	Times mentioned, n	Reasons categorized	Times mentioned, n
Quick diagnosis	10	Misdiagnosis/mistreatment	31
Good disease recognition	5	Lack of recognition of non-bullous variant (n = 2)	
Good awareness	3	High number of doctors seen before diagnosis	6
Disease information provided	3	Lack of disease knowledge	5
Good treatment	3	Symptoms were not taken seriously	2
Good disease knowledge	2	Side-effects of steroids	2
Determined to find the correct diagnosis, after unspecific results of biopsy	2	Long waiting time for referral to specialist	2
		Lack of information	2
		Doctor induced BP by drug prescription	1
		Poor treatment	1
		Many referrals and thereby high costs of care	1
		No biopsy taken	1
Patients satisfied with current patient care, n = 54 (76%)		Patients unsatisfied with current patient care, n = 17 (24%)	
Reasons categorized	Times mentioned, n	Reasons categorized	Times mentioned, n
Satisfied with therapy/in remission	22	Side-effects	5
		Steroids (n = 3)/other therapy (n = 1)	
Experienced/professional dermatologist/care centre	20	Little disease knowledge by doctor	5
Happy with correct diagnosis	3	Insurance issues	4
		Insurance does not cover therapy (n = 3)	
Disease information provided	2	Specialist did not accept the medical insurance (n = 1)	
		Not satisfied with interaction with specialist	2
		No information/support for patients in remission still dealing with skin issues	1
		No satisfactory treatment for itching	1

BP: bullous pemphigoid.

Table SIII. Patients' ranking of unmet needs in pemphigoid diseases per continent

	Unmet need recognized?			Ranking score*
	Yes n (%)	No n (%)	Missing n (%)	
Europe (n = 22)				
1. Need for better treatment options	16 (73)	3 (14)	3 (14)	34
2. Need for awareness	15 (68)	6 (27)	1 (5)	30
3. Need for quicker diagnosis	15 (68)	6 (27)	1 (5)	29
4. Need for guidance on psychological impact	14 (64)	7 (32)	1 (5)	24
5. Need for easily accessible information	12 (55)	9 (41)	1 (5)	21
6. Need for knowledge on impact on comorbidities	15 (68)	5 (23)	2 (9)	16
7. Need better treatment availability	8 (36)	13 (59)	1 (5)	8
8. Need for self-assessment tool	9 (41)	12 (55)	1 (5)	7
North America (n = 48)				
1. Need for better treatment options	31 (65)	2 (4)	15 (31)	54
2. Need for quicker diagnosis	31 (65)	3 (6)	14 (29)	52
3. Need for awareness	30 (63)	2 (4)	16 (33)	45
4. Need better treatment availability	19 (40)	4 (8)	25 (52)	33
5. Need for easily accessible information	22 (46)	5 (10)	21 (44)	32
6. Need for self-assessment tool	19 (40)	4 (8)	25 (52)	22
7. Need for guidance on psychological impact	18 (38)	5 (10)	25 (52)	21
8. Need for knowledge on impact on comorbidities	21 (44)	3 (6)	24 (50)	16
Asia (n = 1)				
No preference noted				

*Ranking score was calculated by awarding 3 points for every time an unmet needs was ranked highest, 2 points if ranked 2nd highest and 1 point if ranked 3rd highest.

Table SIV. Clinicians' ranking of unmet needs in pemphigoid diseases per continent

	Unmet need recognized?			Ranking score*
	Yes n (%)	No n (%)	Missing n (%)	
Europe (n = 21)				
1. Need for labelling of new drugs for the indication pemphigoid	16 (76)	4 (19)	1 (5)	31
2. Need for better recognition of non-bullous cutaneous pemphigoid	17 (81)	3 (14)	1 (5)	24
3. Need for a multidisciplinary approach: building multidisciplinary teams	15 (71)	4 (19)	2 (10)	17
3. Need for easy laboratory tests to diagnose pemphigoid diseases	13 (62)	5 (24)	3 (14)	17
4. Need for consensus on minimal requirements for diagnosis of pemphigoid	16 (76)	4 (19)	1 (5)	16
5. Need for definition of the treatment goal at certain time points during treatment (e.g. at 3 months)	14 (67)	5 (24)	2 (10)	13
6. Need for standardized use of PROMS during treatment	15 (71)	4 (19)	2 (10)	11
7. Need for low threshold for detection of autoantibodies in referral laboratories	12 (57)	7 (33)	2 (10)	0
Asia (n = 4)				
1. Need for easy laboratory tests to diagnose pemphigoid diseases	4 (100)	0 (0)	0 (0)	7
1. Need for a multidisciplinary approach: building multidisciplinary teams	4 (100)	0 (0)	0 (0)	7
2. Need for labelling of new drugs for the indication pemphigoid	4 (100)	0 (0)	0 (0)	6
3. Need for consensus on minimal requirements for diagnosis of pemphigoid	4 (100)	0 (0)	0 (0)	5
4. Need for better recognition of non-bullous cutaneous pemphigoid	4 (100)	0 (0)	0 (0)	4
5. Need for definition of the treatment goal at certain time points during treatment (e.g. at 3 months)	4 (100)	0 (0)	0 (0)	3
6. Need for standardized use of PROMS during treatment	4 (100)	0 (0)	0 (0)	3
7. Need for low threshold for detection of autoantibodies in referral laboratories	3 (75)	0 (0)	1 (25)	2
North America (n = 7)				
1. Need for labelling of new drugs for the indication pemphigoid	7 (100)	0 (0)	0 (0)	14
2. Need for easy laboratory tests to diagnose pemphigoid diseases	7 (100)	0 (0)	0 (0)	9
3. Need for better recognition of non-bullous cutaneous pemphigoid	6 (86)	0 (0)	1 (14)	7
4. Need for low threshold for detection of autoantibodies in referral laboratories	5 (71)	2 (29)	0 (0)	4
4. Need for consensus on minimal requirements for diagnosis of pemphigoid	5 (71)	2 (29)	0 (0)	4
4. Need for definition of the treatment goal at certain time points during treatment (e.g. at 3 months)	5 (71)	2 (29)	0 (0)	4
5. Need for a multidisciplinary approach: building multidisciplinary teams	3 (43)	4 (57)	0 (0)	3
6. Need for standardized use of PROMS during treatment	5 (71)	2 (29)	0 (0)	0

*Ranking score was calculated by awarding 3 points for every time an unmet needs was ranked highest, 2 points if ranked 2nd highest and 1 point if ranked 3rd highest. PROMS: patient-reported outcome measurements.

Table SV. Researchers' ranking of unmet needs in pemphigoid diseases per continent

	Unmet need recognized?			Ranking score*
	Yes n (%)	No n (%)	Missing n (%)	
Europe (n = 18)				
1. Need for more head-to-head randomized controlled trials comparing the effectiveness and safety of current treatments	15 (83)	1 (6)	2 (11)	33
2. Need for understanding of the pathophysiology of pemphigoid for drug development	17 (94)	0 (0)	1 (6)	26
3. Need for understanding trigger mechanism (e.g. infections, drugs) in addition to genetic predisposition	17 (94)	0 (0)	1 (6)	20
4. Need for studies on personalized treatment based on patients characteristics	15 (83)	1 (6)	2 (11)	16
5. Need for humanized animal models that simulate the human eosinophilic pathogenesis and the interactions between human IgG/IgA/IgE with human Fc receptors	11 (73)	3 (17)	4 (22)	10
6. Need for animal models for studying the break of tolerance to desmosomal and hemidesmosomal constituents	12 (67)	3 (17)	3 (17)	5
7. Need for consensus on BPDAI cut-off values for staging disease severity	13 (72)	3 (17)	2 (11)	4
Asia (n = 4)				
1. Need for more head-to-head randomized controlled trials comparing the effectiveness and safety of current treatments	4 (100)	0 (0)	0 (0)	11
2. Need for studies on personalized treatment based on patients characteristics	4 (100)	0 (0)	0 (0)	6
2. Need for animal models for studying the break of tolerance to desmosomal and hemidesmosomal constituents	4 (100)	0 (0)	0 (0)	6
3. Need for consensus on BPDAI cut-off values for staging disease severity	4 (100)	0 (0)	0 (0)	4
4. Need for understanding trigger mechanism (e.g. infections, drugs) in addition to genetic predisposition	4 (100)	0 (0)	0 (0)	3
4. Need for understanding of the pathophysiology of pemphigoid for drug development	4 (100)	0 (0)	0 (0)	3
4. Need for humanized animal models that simulate the human eosinophilic pathogenesis and the interactions between human IgG/IgA/IgE with human Fc receptors	3 (75)	0 (0)	1 (25)	3
North America (n = 6)				
1. Need for understanding of the pathophysiology of pemphigoid for drug development	6 (100)	0 (0)	0 (0)	9
2. Need for animal models for studying the break of tolerance to desmosomal and hemidesmosomal constituents	5 (83)	1 (17)	0 (0)	8
3. Need for humanized animal models that simulate the human eosinophilic pathogenesis and the interactions between human IgG/IgA/IgE with human Fc receptors	6 (100)	0 (0)	0 (0)	7
3. Need for understanding trigger mechanism (e.g. infections, drugs) in addition to genetic predisposition	6 (100)	0 (0)	0 (0)	7
3. Need for more head-to-head randomized controlled trials comparing the effectiveness and safety of current treatments	6 (100)	0 (0)	0 (0)	7
4. Need for studies on personalized treatment based on patients characteristics	5 (83)	1 (17)	0 (0)	1
5. Need for consensus on BPDAI cut-off values for staging disease severity	5 (83)	1 (17)	0 (0)	0

*Ranking score was calculated by awarding 3 points for every time an unmet needs was ranked highest, 2 points if ranked 2nd highest and 1 point if ranked 3rd highest. BPDAI: Bullous Pemphigoid Disease Activity Index.