



# ACARE

Angioedema Centers of Reference and Excellence

**A GA<sup>2</sup>LEN | HAEi NETWORK**

# ANGIOEDEMA PRECEPTORSHIP INDIA

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# FACULTY



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HAEi's Executive Vice President of Global Advocacy and Chief Diversity Officer Sydney, Australia

# ORGANISING COMMITTEE



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## ANGIOEDEMA PRECEPTORSHIP INDIA

# AGENDA

## DATE

09 November 2024

## TARGET AUDIENCE

Specialist physicians, e.g., Allergists, Dermatologists, Gastroenterologists, Pediatricians, ENT, and family physicians,

## NUMBER OF PARTICIPANTS:

Approximately 80 from India and surrounding countries

## INTERNATIONAL FACULTY:

Marcus Magerl  
Thomas Buttgereit

## INDIA FACULTY:

Sunil Dogra  
Ankur Jindal

## HAEi Representative:

Fiona Wardman

## VENUE:

Hyatt Centric Candolim, Goa India

## LOGISTIC SUPPORT:

Neumech Events

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**ANGIOEDEMA  
PRECEPTORSHIP  
INDIA**

# AGENDA



Start Time	Dur.	Time End	Description	Chairs
08:00	00:20	08:20	<b>Registration</b>	
08:20	00:20	08:40	<b>Welcome and introduction to the program</b> <b>Markus Magerl   Sunil Dogra   Ankur Jindal</b> Quick background on the preceptorship program, what we want to achieve, key facts about the hosting center, introduction of participants, key facts on ACARE and UCARE	All Faculty
08:40	00:15	08:55	<b>Multiple choice test - Test your knowledge</b>	All Faculty
08:55	00:20	09:15	<b>What is recurrent angioedema?</b> <b>Markus Magerl</b> Definition of angioedema, definition of recurrent angioedema, classification, nomenclature, what is extravasation, what are the mechanisms of extravasation in mast cell mediator-mediated (mast cell & histamine) and bradykinin-mediated angioedema (contact system), algorithm for differential diagnosis	Sunil Dogra Thomas Buttgereit
09:15	00:10	09:25	<b>Questions and Answers</b> <b>Markus Magerl</b>	Sunil Dogra Thomas Buttgereit
09:25	00:25	09:50	<b>Mast cell-mediated recurrent angioedema</b> <b>Thomas Buttgereit</b> Spectrum, clinical picture, age of onset, prevalence, gender distribution, burden, duration, pathogenesis, diagnostic work up and treatment thereof	Markus Magerl Thomas Buttgereit
09:50	00:10	10:00	<b>Questions and Answers</b> <b>Thomas Buttgereit</b>	Markus Magerl Thomas Buttgereit
10:00	00:30	10:30	<b>Challenges for the diagnosis and management of HAE in India</b> <b>Sunil Dogra</b> <b>Indian Consensus on the diagnosis and management of HAE</b> <b>Ankur Jindal</b>	Markus Magerl Thomas Buttgereit
10:30	00:10	10:40	<b>Questions and Answers</b> <b>Sunil Dogra and Ankur Jindal</b>	Markus Magerl Thomas Buttgereit
10:40	00:20	11:00	<b>Coffee Break</b>	
11:00	00:25	11:25	<b>Bradykinin-mediated angioedema</b> <b>Markus Magerl</b> Spectrum (hereditary vs acquired), clinical picture, age of onset, prevalence, gender distribution, burden, pathogenesis, what questions to include in the history, diagnostic work up, family screening and treatment thereof	Ankur Jindal Sunil Dogra
11:25	00:10	11:35	<b>Questions and Answers</b> <b>Markus Magerl</b>	Ankur Jindal Sunil Dogra

## ANGIOEDEMA PRECEPTORSHIP INDIA

# AGENDA

11:35	00:45	12:20	<b>Interactive case discussion on how to identify the cause of recurrent angioedema in patients</b> <b>Thomas Buttgereit</b> All cases use "What would you do?"-approach 3 cases = 10 min each Q&A = 5 min each	All Faculty
12:20	00:40	13:00	<b>Workshops Room 1 (Group 1)</b> <b>Thomas Buttgereit, Sunil Dogra</b> Management tools and instruments, which ones to use and how to use them (AAS, AE-QoL, AECT, UAS, UCT)  <b>Workshops Room 2 (Group 2)</b> <b>Markus Magerl, Ankur Jindal</b> Tips and tricks for the management of recurrent angioedema, diagnosis, and therapy (algorithms, guidelines, patient diaries, ID card, emergency set)	All Faculty
13:00	01:05	14:05	<b>Lunch</b>	
14:05	00:40	14:45	<b>Workshops Room 1 (Group 2)</b> <b>Thomas Buttgereit, Ankur Jindal</b> Management tools and instruments, which ones to use and how to use them (AAS, AE-QoL, AECT, UAS, UCT)  <b>Workshops Room 2 (Group 1)</b> <b>Markus Magerl, Sunil Dogra</b> Tips and tricks for the management of recurrent angioedema, diagnosis, and therapy (algorithms, guidelines, patient diaries, ID card, emergency set)	All Faculty
14:45	00:40	15:25	<b>Clinical case discussion focused on long term prophylaxis</b> <b>Ankur Jindal and Sunil Dogra</b> 2 cases = 15 min each, Q&A = 10 min each	All Faculty
15:25	00:20	15:45	<b>Future of HAE management</b> <b>Markus Magerl</b> Where HAE management is heading in 2024 and beyond.	Sunil Dogra Ankur Jindal
15:45	00:10	15:55	<b>Questions and Answers</b> <b>Markus Magerl</b>	Sunil Dogra Ankur Jindal
15:55	00:20	16:15	<b>Test for Diploma</b>	All Faculty
16:15	00:30	16:45	<b>Coffee and group Photo</b>	

## ANGIOEDEMA PRECEPTORSHIP INDIA

# AGENDA

16:45	00:10	16:55	<b>HAE International   HAE India</b> <b>Fiona Wardman</b> Patient organisation perspective on angioedema management.	All Faculty
16:55	00:05	17:00	<b>Questions and Answers</b> <b>Fiona Wardman</b>	All Faculty
16:50	00:45	17:45	<b>Test discussion and Award Ceremony</b> <b>Markus Magerl and Thomas Buttgereit</b>	All Faculty
<b>19:10</b>			<b>Dinner</b>	

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# WORKSHOP PROMS

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## PATIENT REPORTED OUTCOME MEASURES

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**AAS** (ENGLISH USA)

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# ANGIOEDEMA ACTIVITY SCORE

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**CONTENT:**

**AAS SCORING TEMPLATE**

**ANGIOEDEMA ACTIVITY SCORE**

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# AAS

(Angioedema Activity Score)

## Scoring Template

The AAS consists of 5 questions as well as an opening question. A score between 0 and 3 is assigned to every answer field. The question scores are summed up to an AAS day sum score, 7 AAS day sum scores to an AAS week sum score (AAS7), and 4 AAS week sum scores may be summed up to an AAS 4-week sum score (AAS28). Accordingly, the minimum and maximum possible AAS scores are 0-15 (AAS day sum score), 0-105 (AAS7), and 0-420 (AAS28).

The opening question may be used to count the number of angioedema affected days during the AAS documentation period but has no score.

Days of week 1															
1	2	3	4	5	6	7									
n	n	n	n	n	n	n	n								
y	y	y	y	y	y	y	y								
1	1	1	1	1	1	1	1								
1	1	1	1	1	1	1	1								
1	1	1	1	1	1	1	1								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
Day sum scores															
Week sum score															

Days of week 2															
1	2	3	4	5	6	7									
n	n	n	n	n	n	n	n								
y	y	y	y	y	y	y	y								
1	1	1	1	1	1	1	1								
1	1	1	1	1	1	1	1								
1	1	1	1	1	1	1	1								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
Day sum scores															
Week sum score															

Days of week 3															
1	2	3	4	5	6	7									
n	n	n	n	n	n	n	n								
y	y	y	y	y	y	y	y								
1	1	1	1	1	1	1	1								
1	1	1	1	1	1	1	1								
1	1	1	1	1	1	1	1								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
Day sum scores															
Week sum score															

Days of week 4															
1	2	3	4	5	6	7									
n	n	n	n	n	n	n	n								
y	y	y	y	y	y	y	y								
1	1	1	1	1	1	1	1								
1	1	1	1	1	1	1	1								
1	1	1	1	1	1	1	1								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
0	0	0	0	0	0	0	0								
1	1	1	1	1	1	1	1								
2	2	2	2	2	2	2	2								
3	3	3	3	3	3	3	3								
Day sum scores															
Week sum score															

4-Week sum score							

# AAS

(Angioedema Activity Score)

## Scoring Template

Example for AAS scoring:

Days of week 1													
1	2	3	4	5	6	7							
n	n	X	X	X	X	X							
X	X	y	y	y	y	y							
							1	X	1	1	1	1	1
							X	X	1	1	1	1	1
							X	X	1	1	1	1	1
							0	0	0	0	0	0	0
							1	1	1	1	1	1	1
							X	X	2	2	2	2	2
							3	3	3	3	3	3	3
							0	0	0	0	0	0	0
							X	X	1	1	1	1	1
2	2	2	2	2	2	2							
3	3	3	3	3	3	3							
0	0	0	0	0	0	0							
1	1	1	1	1	1	1							
X	X	2	2	2	2	2							
3	3	3	3	3	3	3							
0	0	0	0	0	0	0							
1	1	1	1	1	1	1							
X	X	2	2	2	2	2							
3	3	3	3	3	3	3							
Day sum scores													
9	10	0	0	0	0	0							
Week sum score													
19													

Days of week 2													
1	2	3	4	5	6	7							
X	n	n	n	X	X	X							
y	X	X	X	y	y	y							
							1	1	X	X	1	1	1
							1	1	X	X	1	1	1
							1	X	X	1	1	1	1
							0	0	0	0	0	0	0
							1	1	1	X	1	1	1
							2	X	X	2	2	2	2
							3	3	3	3	3	3	3
							0	0	0	0	0	0	0
							1	1	1	X	1	1	1
2	X	X	2	2	2	2							
3	3	3	3	3	3	3							
0	0	0	0	0	0	0							
1	1	1	1	1	1	1							
2	2	2	X	2	2	2							
3	X	X	3	3	3	3							
0	0	0	0	0	0	0							
1	1	1	X	1	1	1							
2	X	X	2	2	2	2							
3	3	3	3	3	3	3							
Day sum scores													
0	10	12	7	0	0	0							
Week sum score													
29													

Days of week 3													
1	2	3	4	5	6	7							
X	X	X	X	X	X	X							
y	y	y	y	y	y	y							
							1	1	1	1	1	1	1
							1	1	1	1	1	1	1
							1	1	1	1	1	1	1
							0	0	0	0	0	0	0
							1	1	1	1	1	1	1
							2	2	2	2	2	2	2
							3	3	3	3	3	3	3
							0	0	0	0	0	0	0
							1	1	1	1	1	1	1
2	2	2	2	2	2	2							
3	3	3	3	3	3	3							
0	0	0	0	0	0	0							
1	1	1	1	1	1	1							
2	2	2	2	2	2	2							
3	3	3	3	3	3	3							
Day sum scores													
0	0	0	0	0	0	0							
Week sum score													
0													

Days of week 4													
1	2	3	4	5	6	7							
X	n	n	n	X	X	X							
y	X	X	X	y	y	y							
							1	1	X	X	1	1	1
							1	X	X	1	1	1	1
							1	X	X	1	1	1	1
							0	0	0	0	0	0	0
							1	1	X	X	1	1	1
							2	X	2	2	2	2	2
							3	3	3	3	3	3	3
							0	0	0	X	0	0	0
							1	1	1	1	1	1	1
2	2	X	2	2	2	2							
3	X	3	3	3	3	3							
0	0	0	0	0	0	0							
1	1	1	X	1	1	1							
2	2	X	2	2	2	2							
3	X	3	3	3	3	3							
0	0	0	0	0	0	0							
1	1	1	X	1	1	1							
2	2	X	2	2	2	2							
3	X	3	3	3	3	3							
Day sum scores													
0	13	10	4	0	0	0							
Week sum score													
27													

4-Week sum score						
75						

# AAS

(Angioedema Activity Score)


## Angioedema activity documentation

Patient name: \_\_\_\_\_

Date questionnaire completed (dd mm yyyy): \_\_\_\_ \_\_\_\_ \_\_\_\_

### Week 1:

**Instructions:** Please document your symptoms retrospectively once a day. Refer to the last 24 hours in each case. Please answer all questions as fully as possible

		Day						
		1	2	3	4	5	6	7
Have you had a swelling episode in the last 24 hours?	no							
	yes							
 <p>Please answer the questions below about this swelling episode during the last 24 hours. If you did not have a swelling episode, leave them blank.</p>								
At what time(s) of day was this swelling episode(s) present? (please select all applicable times)	midnight – 8 a.m.							
	8 a.m. – 4 p.m.							
	4 p.m. - midnight							
How severe is / was the physical discomfort caused by this swelling episode(s) (e.g., pain, burning, itching?)	no discomfort							
	slight discomfort							
	moderate discomfort							
	severe discomfort							
Are / were you able to perform your daily activities during this swelling episode(s)?	no restriction							
	slight restriction							
	severe restriction							
	no activities possible							
Do / did you feel your appearance is / was adversely affected by this swelling episode(s)?	no							
	slightly							
	moderately							
	severely							
How would you rate the overall severity of this swelling episode?	negligible							
	mild							
	moderate							
	severe							

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# AAS

(Angioedema Activity Score)

## Angioedema activity documentation

### Week 2:

**Instructions:** Please document your symptoms retrospectively once a day. Refer to the last 24 hours in each case. Please answer all questions as fully as possible

		Day						
		1	2	3	4	5	6	7
Have you had a swelling episode in the last 24 hours?	no							
	yes							
 <p>Please answer the questions below about this swelling episode during the last 24 hours. If you did not have a swelling episode, leave them blank.</p>								
At what time(s) of day was this swelling episode(s) present? (please select all applicable times)	midnight – 8 a.m.							
	8 a.m. – 4 p.m.							
	4 p.m. - midnight							
How severe is / was the physical discomfort caused by this swelling episode(s) (e.g., pain, burning, itching?)	no discomfort							
	slight discomfort							
	moderate discomfort							
	severe discomfort							
Are / were you able to perform your daily activities during this swelling episode(s)?	no restriction							
	slight restriction							
	severe restriction							
	no activities possible							
Do / did you feel your appearance is / was adversely affected by this swelling episode(s)?	no							
	slightly							
	moderately							
	severely							
How would you rate the overall severity of this swelling episode?	negligible							
	mild							
	moderate							
	severe							

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
# AAS

(Angioedema Activity Score)

## Angioedema activity documentation

### Week 3:

**Instructions:** Please document your symptoms retrospectively once a day. Refer to the last 24 hours in each case. Please answer all questions as fully as possible

		Day						
		1	2	3	4	5	6	7
Have you had a swelling episode in the last 24 hours?	no							
	yes							
 <b>Please answer the questions below about this swelling episode during the last 24 hours. If you did not have a swelling episode, leave them blank.</b>								
At what time(s) of day was this swelling episode(s) present? (please select all applicable times)	midnight – 8 a.m.							
	8 a.m. – 4 p.m.							
	4 p.m. - midnight							
How severe is / was the physical discomfort caused by this swelling episode(s) (e.g., pain, burning, itching?)	no discomfort							
	slight discomfort							
	moderate discomfort							
	severe discomfort							
Are / were you able to perform your daily activities during this swelling episode(s)?	no restriction							
	slight restriction							
	severe restriction							
	no activities possible							
Do / did you feel your appearance is / was adversely affected by this swelling episode(s)?	no							
	slightly							
	moderately							
	severely							
How would you rate the overall severity of this swelling episode?	negligible							
	mild							
	moderate							
	severe							

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# AAS

(Angioedema Activity Score)

## Angioedema activity documentation

### Week 4:

**Instructions:** Please document your symptoms retrospectively once a day. Refer to the last 24 hours in each case. Please answer all questions as fully as possible

		Day						
		1	2	3	4	5	6	7
Have you had a swelling episode in the last 24 hours?	no							
	yes							
 <b>Please answer the questions below about this swelling episode during the last 24 hours. If you did not have a swelling episode, leave them blank.</b>								
At what time(s) of day was this swelling episode(s) present? (please select all applicable times)	midnight – 8 a.m.							
	8 a.m. – 4 p.m.							
	4 p.m. - midnight							
How severe is / was the physical discomfort caused by this swelling episode(s) (e.g., pain, burning, itching?)	no discomfort							
	slight discomfort							
	moderate discomfort							
	severe discomfort							
Are / were you able to perform your daily activities during this swelling episode(s)?	no restriction							
	slight restriction							
	severe restriction							
	no activities possible							
Do / did you feel your appearance is / was adversely affected by this swelling episode(s)?	no							
	slightly							
	moderately							
	severely							
How would you rate the overall severity of this swelling episode?	negligible							
	mild							
	moderate							
	severe							

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# **AECT** (ENGLISH USA)

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# **ANGIOEDEMA CONTROL TEST**

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## **CONTENT:**

**AECT INSTRUCTIONS AND SCORING**

**ANGIOEDEMA CONTROL TEST – 4 WEEK RECALL**

**ANGIOEDEMA CONTROL TEST – 3 MONTH RECALL**

**ANGIOEDEMA  
PRECEPTORSHIP  
INDIA**

# Angioedema Control Test (AECT)

## Instructions and Scoring

The AECT is a self-administered 4-item patient-reported outcome measure for patients with recurrent angioedema. Patients are asked to read the instructions of the AECT and to then provide answers to all 4 AECT-questions. Subsequently, the AECT score can be computed. To this end, scores between 0 and 4 are assigned to the answer options of every AECT question and the scores of the chosen answer options are summed up. Accordingly, the minimum and maximum AECT scores are 0 and 16, with higher scores indicating a higher level of angioedema control. Both AECT versions (recall period 4-weeks and recall period 3 months) are scored identically. Below you find a scoring example.

### Example (Completed AECT 4-week questions):

1. In the last 4 weeks, how often have you had angioedema?

<input type="radio"/> very often (0 points)	<input checked="" type="radio"/> often (1 point)	<input type="radio"/> sometimes (2 points)	<input type="radio"/> seldom (3 points)	<input type="radio"/> not at all (4 points)
--	---	---	--	--

2. In the last 4 weeks, how much has your quality of life been affected by angioedema?

<input checked="" type="radio"/> very much (0 points)	<input type="radio"/> much (1 point)	<input type="radio"/> somewhat (2 points)	<input type="radio"/> a little (3 points)	<input type="radio"/> not at all (4 points)
--	---	--	--	--

3. In the last 4 weeks, how much has the unpredictability of your angioedema bothered you?

<input checked="" type="radio"/> very much (0 points)	<input type="radio"/> much (1 point)	<input type="radio"/> somewhat (2 points)	<input type="radio"/> a little (3 points)	<input type="radio"/> not at all (4 points)
--	---	--	--	--

4. In the last 4 weeks, how well has your angioedema been controlled by your therapy?

<input type="radio"/> not at all (0 points)	<input checked="" type="radio"/> a little (1 point)	<input type="radio"/> somewhat (2 points)	<input type="radio"/> well (3 points)	<input type="radio"/> very well (4 points)
--	--	--	--	---

### Scoring of example and interpretation:

AECT score = score question 1 (1point)  
                  + score question 2 (0 points)  
                  + score question 3 (0 points)  
                  + score question 4 (1 point)

AECT score = 2 points

Interpretation: An AECT score of 2 points indicates poorly controlled disease.

(A cutoff-value of 10 was found to have the best balance of sensitivity (76%) and specificity (84%) to identify patients with well-controlled angioedema (AECT score <10 points indicates poorly controlled recurrent angioedema, AECT score ≥10 points indicates well-controlled recurrent angioedema). However, the cut-off value may be adjusted to the purpose of the AECT application, e.g. if the sensitivity is more important than specificity or vice versa. Results of both AECT versions (4-week version and 3 months version) are interpreted identically.)

Reference: Weller et al. Validation of the Angioedema Control Test (AECT) - a patient reported outcome instrument for assessing angioedema control. J Allergy Clin Immunol Pract 2020 (doi.org/10.1016/j.jaip.2020.02.038).

## Angioedema Control Test (AECT)

Patient name: \_\_\_\_\_

Date: (dd mmm yyyy): \_\_\_\_ \_\_\_\_ \_\_\_\_

Date of birth (dd mmm yyyy): \_\_\_\_ \_\_\_\_ \_\_\_\_

**Instructions:** You have recurrent swelling referred to as angioedema. Angioedema is a temporary swelling of the skin or mucous membranes which can occur in any part of the body but most commonly involves the lips, eyes, tongue, hands and feet and which can last from hours to days. Some patients develop abdominal angioedema, which is often not visible but painful. Some forms of swelling can also be associated with hives also known as urticaria.

The following four questions assess your current state of health. For each question, please choose the answer from the five options that *best fits your situation*. Please answer *all questions* and please provide *only one answer to each question*.

1. In the last 4 weeks, how often have you had angioedema?  
☐ very often    ☐ often    ☐ sometimes    ☐ seldom    ☐ not at all
2. In the last 4 weeks, how much has your quality of life been affected by angioedema?  
☐ very much    ☐ much    ☐ somewhat    ☐ a little    ☐ not at all
3. In the last 4 weeks, how much has the unpredictability of your angioedema bothered you?  
☐ very much    ☐ much    ☐ somewhat    ☐ a little    ☐ not at all
4. In the last 4 weeks, how well has your angioedema been controlled by your therapy?  
☐ not at all    ☐ a little    ☐ somewhat    ☐ well    ☐ very well

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# Angioedema Control Test

## (AECT)

Patient name: \_\_\_\_\_

Date: (dd mmm yyyy): \_\_\_\_ \_\_\_\_ \_\_\_\_

Date of birth (dd mmm yyyy): \_\_\_\_ \_\_\_\_ \_\_\_\_

**Instructions:** You have recurrent swelling referred to as angioedema. Angioedema is a temporary swelling of the skin or mucous membranes which can occur in any part of the body but most commonly involves the lips, eyes, tongue, hands and feet and which can last from hours to days. Some patients develop abdominal angioedema, which is often not visible but painful. Some forms of swelling can also be associated with hives also known as urticaria.

The following four questions assess your current state of health. For each question, please choose the answer from the five options that *best fits your situation*. Please answer *all questions* and please provide *only one answer to each question*.

1. In the last 3 months, how often have you had angioedema?

☐ very often      ☐ often      ☐ sometimes      ☐ seldom      ☐ not at all

2. In the last 3 months, how much has your quality of life been affected by angioedema?

☐ very much      ☐ much      ☐ somewhat      ☐ a little      ☐ not at all

3. In the last 3 months, how much has the unpredictability of your angioedema bothered you?

☐ very much      ☐ much      ☐ somewhat      ☐ a little      ☐ not at all

4. In the last 3 months, how well has your angioedema been controlled by your therapy?

☐ not at all      ☐ a little      ☐ somewhat      ☐ well      ☐ very well

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# **AE-QOL** (ENGLISH USA)

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# **ANGIOEDEMA QUALITY OF LIFE QUESTIONNAIRE**

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## **CONTENT:**

**INSTRUCTIONS FOR EVALUATION OF THE AE-QOL**

**AE-QOL QUALITY OF LIFE QUESTIONNAIRE FOR  
PATIENTS WITH RECURRENT SWELLING EPISODES**

**ANGIOEDEMA  
PRECEPTORSHIP  
INDIA**

# Instructions for evaluation of the AE-QoL

## The structure of AE-QoL

The AE-QoL consists of four domains and a total score:

Domain	Item (Question)
Functioning	1. Impairment of work
	2. Impairment of physical activity
	3. Impairment of spare time activities
	4. Impairment of social relations
Fatigue/Mood	6. Difficulties of falling asleep
	7. Waking up during the night
	8. Feeling tired during the day
	9. Difficulties in concentrating
	10. Feeling downhearted
Fears/Shame	12. Feeling burdened at having swellings
	13. Fear of new suddenly appearing swellings
	14. Fear of increased frequency of swellings
	15. Ashamed to visit public places
	16. Embarrassed by the appearance of swellings
	17. Fear of long term negative drug effects
Nutrition	5. General limitations in foods and eating
	11. Limitations in the selection of food and beverages
Total Score	Items 1 to 17

## How to calculate AE-QoL domain scores and the AE-QoL total score

AE-QoL is meant to be evaluated by determining its four individual domain scores (application as a profile instrument) but it may also be used to determine a total score (application as an index instrument):

Each item answered by the patient scores between 0 and 4 points depending on the answer option chosen by the patient. The 1<sup>st</sup> answer option gets 0 points, the 2<sup>nd</sup> option 1 point, the 3<sup>rd</sup>



option 2 points, etc. (Never=0, Rarely=1, Occasionally=2, Often=3, Very often=4)

The AE-QoL domain scores as well as the AE-QoL total score are calculated by using the following formula:

$$\frac{\text{Sum of all completed items}}{\text{Max. possible sum of all completed items}} \times 100 = \text{AE-QoL Score}$$

### Computation of Total Score:

*Example 1:* All items were completed (Max. possible sum: 68 points)  
Sum of all 17 completed items: 41 points

$$\frac{41}{68} \times 100 = 60 \rightarrow \text{AE-QoL Total Score} = 60 \text{ out of possible 100 points}$$

*Example 2:* 2 items were not completed (Max. possible sum: 60 points).  
Sum of all 15 completed items: 41 points

$$\frac{41}{60} \times 100 = 68 \rightarrow \text{AE-QoL Total Score} = 68 \text{ out of possible 100 points}$$

### Computation of Domain Scores (Example: Fears/Shame):

*Example:* Sum of all 6 completed items: 14 points  
Max possible sum: 24 points

$$\frac{14}{24} \times 100 = 58 \rightarrow \text{Fears/Shame Score} = 58 \text{ out of possible 100 points}$$

### Remarks

Since only answered items are included in the computation (and the calculated domain and total scores are not raw scores but linear transformations to a 0 to 100 scale), the calculated scores are not or only little influenced by missing items.

An AE-QoL domain score should not be calculated if more than one item is left unanswered in that domain. The AE-QoL total score should not be calculated if more than 25% of items (>4 items) are left unanswered.

The minimal and highest possible domain and total scores are 0 and 100, respectively.

### References:

Weller K, Groffik A, Magerl M, Tohme N, Martus P, Krause K, Metz M, Staubach P, Maurer M. Development and construct validation of the angioedema quality of life questionnaire. Allergy. 2012; 67(10): 1289-98.

# AE-QoL

## Quality of Life Questionnaire for Patients with Recurrent Swelling Episodes

Patient name: \_\_\_\_\_

Date questionnaire completed (dd mmm yyyy): \_\_\_\_ \_\_\_\_ \_\_\_\_

**Instructions:** This questionnaire asks a number of questions. Please read each question carefully and choose from the five answers the one that fits best for you. Please do not think too long about the questions; be sure to answer all of the questions and to give only one answer to each question, i.e., to check only one box for each question.

Indicate how often within the <b>last 4 weeks</b> you have been restricted in the areas of your daily life listed below because of swelling episodes (angioedema). (regardless of whether or not you have actually experienced swelling episodes during that time period)	Never	Rarely	Occasionally	Often	Very often
<b>1. Work</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>2. Physical activity</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>3. Leisure time</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>4. Social relations</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>5. Eating and drinking</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the following questions we would like to get more details about the difficulties and problems that may be associated with your recurrent swelling episodes (angioedema) (during the <b>last 4 weeks</b> )	Never	Rarely	Occasionally	Often	Very often
<b>6. Do you have difficulty falling asleep?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>7. Do you wake up during the night?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>8. Are you tired during the day because you are not sleeping well at night?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>9. Do you have trouble concentrating?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>Never</b>	<b>Rarely</b>	<b>Occasionally</b>	<b>Often</b>	<b>Very often</b>
<b>10. Do you feel depressed?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>11. Do you have to limit your choices of food or beverages?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12. Do the swelling episodes place a burden on you?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>13. Are you afraid that a swelling episode could occur suddenly?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>14. Are you afraid that the frequency of the swelling episodes might increase?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>15. Are you ashamed to go out in public because of the swelling episodes?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>16. Do the swelling episodes make you embarrassed or self-conscious?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>17. Are you afraid that the treatment of the swelling episodes could have negative long-term effects for you?</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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# ANGIOEDEMA GUIDELINES



## The international WAO/EAACI guideline for the management of hereditary angioedema The 2021 revision and update

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## ANGIOEDEMA PRECEPTORSHIP INDIA

# URTICARIA GUIDELINES



The international  
EAACI/GA<sup>2</sup>LEN/EuroGuiDerm/APAAACI  
guideline for the definition,  
classification, diagnosis, and  
management of urticaria  
The 2021 revision and update

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**ANGIOEDEMA  
PRECEPTORSHIP  
INDIA**

# ANGIOEDEMA PRECEPTORSHIP SOUTH KOREA



Thank you to all the faculty and participants for taking part in the ACARE *LevelUp* Preceptorship: "State of the art management of recurrent angioedema and hands on training" intended for health care professionals from India and surrounding countries.

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