

VASCERN Summer School 2025

Program



Erasmus+



Co-funded by
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of the European Union



VASCERN



Program Overview

Online Module (30 hrs)*

February 3, 2025 to May 30, 2025

Module 1: Introduction (1 hr 30 min) – Week 1

WEEK 1: February 3
to 7, 2025

**Session 1 (1 hour and 30 minutes live session):
Introduction to the VASCERN Summer School**

- Organization of the course
- Presentation
- Questions

**Introduction to rare diseases
National and European Organizations for
Rare Vascular Diseases**

- The European Vascular Reference Network in Europe (VASCERN)
- The rare vascular disease networks in Europe (national and scientific societies)

Module 2: Methods (1 hr 30 min) – Week 2

WEEK 2: February 10
to 14, 2025

**Session 2 (1 hour pre-recorded session):
Transversal module on aortic and vascular
imaging**

**Session 3 (30-minute live session): Discussion
and Q&A on the transversal module**

Module 3: Translational Research and Genetics (17 hrs) – Weeks 3-11

WEEK 3-4: February 17 to 28 2025	<p>Session 4 (4 hours): Adapted from EJP-RD trainings, available online at any time</p> <ul style="list-style-type: none"> From bench to preclinical studies
	<p>Session 5 (30-minute live session): Discussion and Q&A on Session 5</p>
WEEK 5-6: March 3 to 14, 2025	<p>Session 6 (4 hours): Adapted from EJP-RD trainings, available online at any time</p> <ul style="list-style-type: none"> Preclinical models for rare diseases
	<p>Session 7 (30-minute live session): Discussion and Q&A on Session 6</p>
WEEK 7: March 17 to 21, 2025	<p>Session 8 (2 hours): Adapted from EJP-RD trainings, available online at any time</p> <ul style="list-style-type: none"> Clinical trials for rare diseases
	<p>Session 9 (30-minute live session): Discussion and Q&A on Session 8</p>
WEEK 8-9: March 24 to April 4, 2025	<p>Session 10 (4 hours): Adapted from EJP-RD trainings, available online at any time</p> <ul style="list-style-type: none"> Interpretation of genetic results
	<p>Session 11 (30-minute live session): Discussion and Q&A on Session 10</p>
WEEK 10: April 7 to 11, 2025	<p>Session 12 (1 hour live session): Final discussion and Q&A session with a VASCERN researcher on Module 3</p>

Easter Break: from 14th to 21st April 2025

Module 4: ePAG and Patients Organizations (1 hr 30 min) - Week 14

WEEK 11-12: April 22 to 30, 2025

Session 13 (1 hour and 30 minutes live session): ePAG and patients organizations

Module 5: Patient Therapeutic Education (1 hr) - Week 14

WEEK 11-12: April 22 to 30, 2025

Session 14 (30-minute pre-recorded session): Patient therapeutic education

Session 15 (1 hour live session): Discussion and Q&A on Session 14

Break: from 1st to 9th May 2025

Module 6: Psychology (4 hrs) - Week 13-14

WEEK 13-14: May 12 to 23, 2025

Session 16 (2 hours pre-recorded webinars): Psychological support

Webinar 1

- Specificity of the genetic diagnosis announcement with the double impact on the person and his/her family
- Screening of relatives
- Pre-symptomatic diagnosis and its specificities

Module 6: Psychology (4 hrs) - Week 13-14

WEEK 13-14: May 12
to 23, 2025

Webinar 2

- Prenatal diagnosis
- Pre-implantation genetic testing
- The announcement to the child

Webinar 3

- Psychological impact of clinical trials and new treatments

Session 17 (1 hour live session): Discussion and Q&A on Session 16

Session 18 (30-minute pre-recorded session): Quality of life and rare vascular diseases

Session 19 (30-minute live session): Discussion and Q&A on Session 18

Module 7: Final module (1 hr 30 min) – Week 15

WEEK 15: May 26 to
30, 2025

Session 20 (1 hour 30 minute live session):

- Wrap up, discussion, and Q&A session of the online module
- Practical issues about the onsite

* Please note that the program may be subject to change based on the lecturer's availability.

Onsite Module (40 hrs)*

Day 1: Monday, September 15, 2025

8:45-9:00: Welcome & Introduction	
9:00-16:10: Heritable Thoracic Aortic Disease (HTAD) (6 hrs)	
9:00-9:45	INTRODUCTION AND GENETICS: Introduction to Marfan syndrome and related disorders: genetics and different phenotypes (children and adults)
9:45-10:30	DIAGNOSIS: Making a diagnosis: initial assessment, imaging, interpretation of genetic results
10:30-11:00 Coffee break	
11:00-12:05	TREATMENT: Medical therapy, surgical indications and the different surgeries, Q&A
12:05-13:05 Lunch break	
13:05-14:40	LIVING WITH HTAD: Follow-up, Sports and holidays, Pregnancy (cardiology follow-up, transmission and gynecology), Sexuality and social life (body image, recreational drugs, piercings, tattoos), Q&A session
14:40-15:40	CASE DISCUSSION

15:40-16:10	PATIENT'S EXPERIENCE + Q&A SESSION
16:10-16:30: End of the HTAD Course / Break	
16:30-18:30: Medium Sized Arteries (MSA) – PART I (2 hrs)	
16:30-17:30	INTRODUCTION AND GENETICS: Vascular Ehlers-Danlos syndrome: the different phenotypes (children and adults), genetics, initial assessment and differential diagnosis (other EDS)
17:30-18:00	MSA DISSECTION: Diagnostic work-up, differential diagnosis, MSA dissection
18:00-18:30	MANAGEMENT OF MSA DISSECTION: Management of arterial dissection or aneurysm
18:30 End of the day	

Day 2: Tuesday, September 16, 2025

9:00-13:15: Medium Sized Arteries (MSA) – PART II (4 hrs)	
9:00-11:00	LIVING WITH vEDS: Management of arterial dissection or aneurysm, pregnancy (vascular follow-up, transmission and gynecology) and organ complications
11:00-11:15 Coffee break	

11:15-11:45	CASE DISCUSSION
11:45-12:45	PATIENT'S EXPERIENCE
12:45-13:15	END OF THE SESSION: Q&A / Wrap-up
<i>13:15-14:15 End of the MSA Course / Lunch Break</i>	
14:15-17:30: Neurovascular Diseases (NEUROVASC) – PART I: CADASIL (3 hrs)	
14:15-14:45	INTRODUCTION AND GENETICS: Introduction to CADASIL - Physiopathology and Genetics
14:45-15:15	CLINICAL EXPRESSION AND NATURAL HISTORY: CADASIL
15:15-15:45	DIAGNOSIS in pre-symptomatic and symptomatic patients
15:45-16:00	Management and patient care
<i>16:00-16:30 Break</i>	
16:30-17:00	CASE DISCUSSION
17:00-17:30	PATIENT'S EXPERIENCE + Q&A SESSION
<i>17:30 End of the day</i>	

9:00-12:15: Neurovascular Diseases (NEUROVASC) – PART II: MOYAMOYA ANGIOPATHY (3 hrs)	
9:00-9:30	INTRODUCTION TO MOYAMOYA ANGIOPATHY: Definition and pathophysiology
9:30-10:00	CLINICAL PRESENTATION AND NATURAL HISTORY
10:00-10:30	DIAGNOSIS: Initial assessment and differential diagnosis
10:30-11:00 Coffee Break	
11:00-11:45	Risk and prevention in daily life, medical and surgical treatment
11:45-12:15	CASE DISCUSSION
12:15-13:15: End of the NEUROVASC courses / Lunch break	
13:15-17:30: Vascular Anomalies (VASCA) – PART I (4 hrs)	
13:15-13:25	INTRODUCTION: What are vascular anomalies (VAs), organization of the course
13:25-13:35	PATIENT PERSPECTIVE: “Living with a vascular anomaly” (Patient movie)

13:35-14:00	CURRENT CLASSIFICATION OF VASCULAR ANOMALIES
<i>14:00-14:15 Break</i>	
14:15-14:45	TREATMENT OPTIONS: Vascular Anomalies - medical treatment, IR options, surgical options
14:45-15:00	PATIENT PERSPECTIVE: "Living with a vascular anomaly" (Patient movie)
15:00-16:30	CASE DISCUSSION: Medical, Laser, IR, Surgery and differential diagnosis
16:30-17:00	Surgical videos, IR videos, etc.
17:00-17:30	WRAP-UP Day 1: Questions, quiz, feedback, discussion
<i>17:30 End of the day</i>	

Day 4: Thursday, September 18, 2025

9:00-11:10: Vascular Anomalies (VASCA) – PART II (2 hrs)	
9:00-9:30	INTRODUCTION TO PART II: Recap of Day 1 - discussion on the quiz

09:30-09:50	CAUSES OF VASCULAR ANOMALIES
09:50-10:20	Targeted medical treatment
10:20-10:30	Combined syndromes
10:30-10:50	Multidisciplinary clinic + treatment strategy discussion from a patient perspective
10:50-11:00	END OF THE COURSE: Final discussion, ask for feedback on the courses
<i>11:00-11:15 End of VASCA course / Coffee Break</i>	
11:15-18:30: Pediatric and Primary Lymphedema (PPL) (6 hrs)	
11:15-12:15	INTRODUCTION AND GENETICS: Pediatric and Primary Lymphedema: Physiopathology and Genetics
12:15-13:15	CLINICAL EXPRESSION AND NATURAL HISTORY: Clinical expression and natural history of PPL
<i>13:15-14:15 Lunch Break</i>	
14:15-15:00	DIAGNOSIS: Diagnosis of PPL

15:00-16:00	TREATMENT: Treatment of PPL (conservative or surgical) and complications
16:00-16:15 Break	
16:15-16:45	GENETICS WORKSHOP: Making a genealogic tree
16:45-17:30	CASE DISCUSSION: Practical cases
17:30-18:30	PATIENT'S EXPERIENCE + Q&A SESSION
18:30 End of the day	

Day 5: Friday, September 19 2025

9:00-16:30: Hereditary Hemorrhagic Telangiectasia (HHT) (6 hrs)	
9:00-9:10	INTRODUCTION: VASCERN HHT Video (HHT from VASCERN HHT) (8 minutes)
9:10-9:45	PATIENT'S EXPERIENCE: Medical history and findings
9:45-10:30	GENETICS PATHOPHYSIOLOGY: Basic genetics, why HHT develops, life expectancy

10:30-11:00 Break	
11:00-13:15	<p>CLINICAL EXPRESSION, NATURAL HISTORY AND TREATMENT:</p> <ol style="list-style-type: none"> 1. Nosebleeds 2. Organ involvement and other issues 3. New treatments 4. Common diseases that can mimic HHT in usual medical practice (other causes of bleeding, breathlessness, etc.) 5. Other conditions your HHT patients will have
13:15-14:15 Lunch Break	
14:15-15:45	<p>CASE DISCUSSION: Workshop - structured initial assessment, clinical management and follow-up for several scenarios</p>
15:45-16:30	<p>SUMMARY + Q&A SESSION</p>
16:30 End of the HHT course / End of the day	

Day 6: Saturday, September 20, 2025

9:00-13:00: Final activity on Psychology - role-plays with patients and doctors (3 hrs 30 min)	
9:30-12:30	<p>COMMUNICATION SKILLS THROUGH ROLE PLAYS WITH PATIENTS AND DOCTORS</p> <ul style="list-style-type: none"> • Announcing the diagnosis

	<ul style="list-style-type: none"> • Announcing surgery • Dealing with the aftermath of surgery
12:30-13:00	END OF THE ACTIVITY: Debrief of the experience with the participants
13:00-13:30 Final Activity (30 min)	
13:00-13:30	CLOSING SESSION: Debrief of the experience with the participants
<i>13:30 End of the VASCERN Summer School</i>	

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