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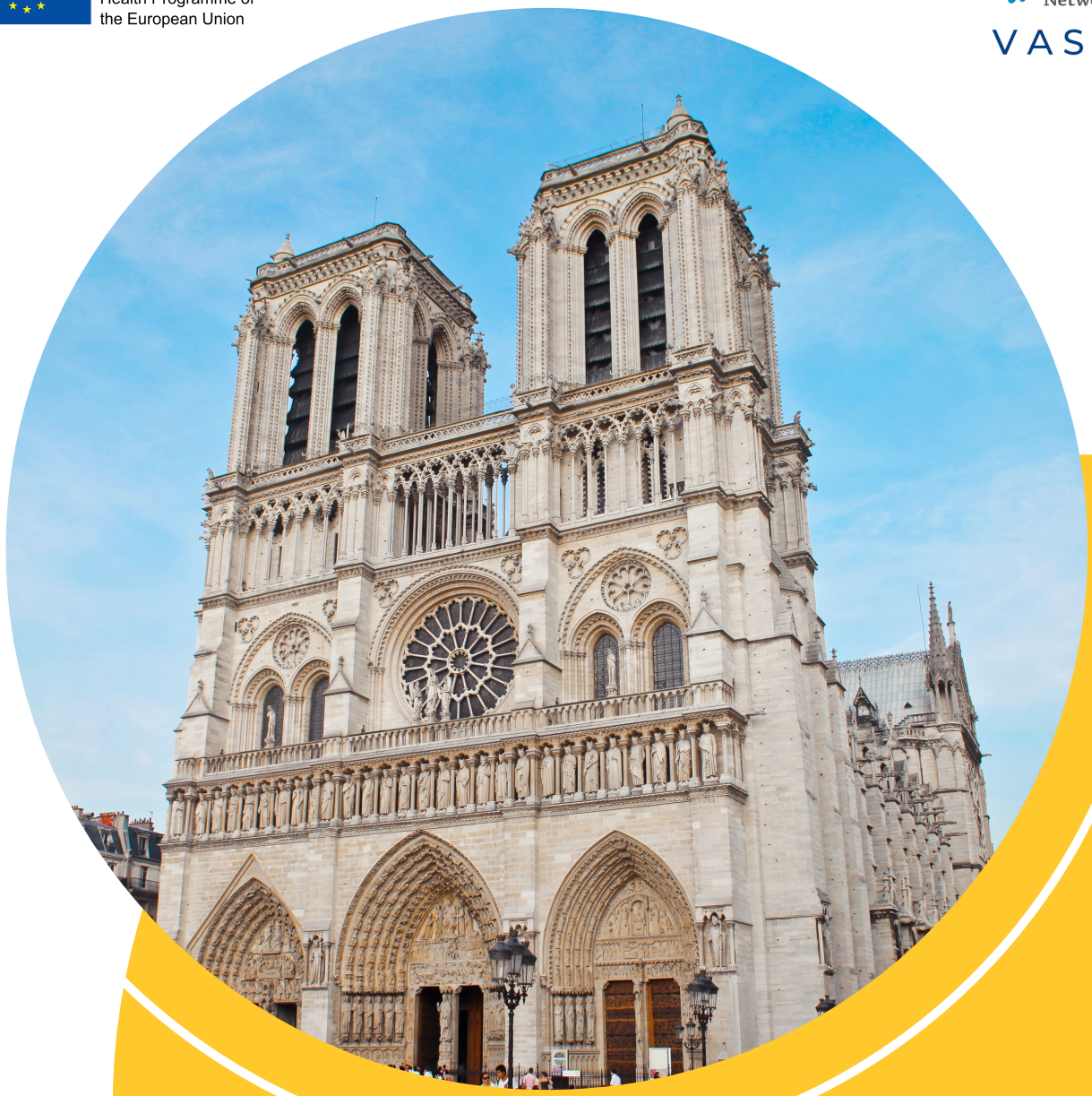
VASCERN



VASCERN SUMMER SCHOOL 2024

Program

Erasmus+

Program Online Module of the VASCERN Summer School (29h)*

Module 1: Introduction (2h30)

Module 1: Introduction (2h30) – Week 1-2	
WEEK 1: 5th to 9th February 2024	**Session 1 – Introduction to the VASCERN Summer School (30 min live session)** • Organization of the course • Presentation • Questions
	Introduction to Rare Diseases **(1h live session)**
WEEK 2: 12th to 16th February 2024	**Session 2 – National and European organization of Rare Vascular Diseases (1h live session: 45 min presentation + 15 min Q&A and discussion)** • The European Reference Network in Europe (VASCERN) • The rare vascular disease networks in Europe (national and scientific societies)

Module 2: Methods (1h30)

Module 2: Methods (1h30) – Week 3	
WEEK 2: 19th to 23rd February 2024	**Session 3 – Transversal module on aortic and vascular imaging (1h pre-recorded session)**
	Session 4 – Discussion and Q&As on the transversal module (30 min live session)

Module 3: Translational research and genetics (17h)

Module 3: Translational research and genetics (17h) – Week 4-11	
WEEK 4-5: 26th February to 8th March 2024	**Session 5 – Adapted from EJP-RD trainings, available online anytime** • From bench to preclinical studies **(4h in total)**
	Session 6 – Discussion and Q&As on Session 5 (30 min live session)
WEEK 6-7: 11th to 22nd March 2024	**Session 7 – Adapted from EJP-RD trainings, available online anytime** • Preclinical models for rare diseases **(4h in total)**
	Session 8 – Discussion and Q&As on Session 7 (30 min live session)
WEEK 8: 25th to 29th March 2024	**Session 9 – Adapted from EJP-RD trainings, available online anytime** • Clinical trials for rare diseases **(2h in total)**
	Session 10 – Discussion and Q&As on Session 9 (30 min live session)
WEEK 9-10: 1st to 12th April 2024	**Session 11 – Adapted from EJP-RD trainings, available online anytime** • Interpretation of genetic results **(4h in total)**
	Session 12 – Discussion and Q&As on Session 11 (30 min live session)
WEEK 11: 15th to 19th April 2024	**Session 13 – Final discussion and Q&A session with a VASCERN researcher on Module 3 (1h live session)**

Module 4: Psychology (4h)

Module 4: Psychology (4h) – Week 11-13	
WEEK 11-12: 15th to 26th April 2024	**Session 14 – Psychological support (2h, pre-recorded webinars - 4 webinars of 30')** • Specificity of the diagnostic communication in genetics with the double impact on the person and his/her family • Screening of relatives • Pre-symptomatic diagnosis and its specificities • Prenatal diagnosis • Communicating the diagnosis to a child • Psychological impact of clinical trials and new treatments • Family testimonies with perhaps an expert patient
	Session 15 – Discussion and Q&As on Session 14 (1h live session)
WEEK 13: 29th April to 3rd May 2024	**Session 16 – Quality of life and rare vascular diseases (1h live session)**

Module 5: Patient therapeutic education (1h)

Module 5: Patient therapeutic education (1h) - Week 14	
WEEK 14: 6th to 10th May 2024	**Session 17 – Patient therapeutic education (1h live session)**

Module 6: ePAG and patients organisations (1h30)

Module 5: Patient therapeutic education (1h) - Week 14	
WEEK 14: 6th to 10th May 2024	**Session 18 – ePAG and patients organisations (1h30 live session)**

Module 7: Final module (1h30)

Module 7: Final module (1h30) – Week 15	
WEEK 15: 13th to 17th May 2024	**Session 19 – Wrap up, discussion and Q&A session of the online module (1h30 live session)**

** Please note that the program may be subject to changes according to the lecturer's availability.*

Program Onsite Part of the VASCERN Summer School 2024 (40 h)*

Day 1: Monday 23rd September 2024

8.45-9.00: Welcome & Introduction	
9.00-16.10: Heritable Thoracic Aortic Disease (HTAD) (6h)	
9.00-10.00	**INTRODUCTION AND GENETICS:** Introduction to Marfan syndrome and related disorders: genetics and different phenotypes (children and adults)
10.00-10.45	**DIAGNOSIS:** Making a diagnosis: initial assessment, imaging, interpretation of genetic results
10h45-11h00: Coffee Break	
11.00-12.35	**LIVING WITH THE DISEASE:** 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
12h35-13h35: Lunch Break	
13.35-15.10	**TREATMENT:** Medical therapy, Surgical indications and Types of Surgeries, Q&As
15.10-15.40	**CASE DISCUSSION**
15.40-16.10	**PATIENT'S EXPERIENCE + Q&A SESSION**
16h10-16h30: Break	
16h30-18h30: Medium Sized Arteries (MSA) – PART I (2h)	
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	**ETIOLOGY:** Etiology in a patient with arterial dissection
18.00-18.30	**LIVING WITH THE DISEASE:** Treatment: Follow-up, sports, medical treatment
18h30: End of the day	

Day 2: Tuesday 24th September 2024

9.00-13.15: Medium Sized Arteries (MSA) – PART II (4h)	
9.00-10.00	**LIVING WITH THE DISEASE:** Management of arterial dissection or aneurysm
10.00-11.00	Pregnancy (vascular follow-up, transmission and gynecology) and organ complications
11h00-11h15: Coffee Break	
11.15-12.15	**CASE DISCUSSION**
12.15-13.15	**PATIENT'S EXPERIENCE + Q&A SESSION**
13.15-14.15: Lunch Break	
14.15-17.30: Neurovascular diseases (NEUROVASC) – PART I: CADASIL (3h)	
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:** Initial assessment and differential diagnosis of CADASIL
15.45-16.15	**LIVING WITH THE DISEASE:** Management, follow up of CADASIL

16.15-16.30: Break	
16.30-17.00	**CASE DISCUSSION. GENETICS WORKSHOP:** Making a genealogic tree, practical cases
17.00-17.30	**PATIENT'S EXPERIENCE + Q&A SESSION**
17.30: End of the day	

Day 3: Wednesday 25th September 2024

9.00-12.15: Neurovascular diseases (NEUROVASC) – PART II: MOYAMOYA ANGIOPATHY (3h)	
9.00-9.30	**INTRODUCTION AND GENETICS –** Moyamoya Angiopathy: Physiopathology and Genetics
9.30-10.00	**CLINICAL EXPRESSION AND NATURAL HISTORY –** Moyamoya Angiopathy
10.00-10.30	**DIAGNOSIS:** Initial assessment and differential diagnosis of Moyamoya Angiopathy
10.30-10.45: Coffee Break	
10.45-11.15	**LIVING WITH THE DISEASE:** Management, follow up of Moyamoya Angiopathy
11.15-11.45	**CASES DISCUSSION. GENETICS WORKSHOP:** making a genealogic tree, practical cases
11.45-12.15	**PATIENT'S EXPERIENCE + Q&A SESSION**
12.15-13.15: Lunch Break	
13.15-17.30: Vascular Anomalies (VASCA) – PART I (4h)	
13.15-13.20	The patient perspective "Living with a superficial vascular anomaly" (Patient movie)

13.20-14.00	What are vascular anomalies: current classification
14.00-14.45	What is known about the causes of vascular anomalies?
14.45-15.00: Break	
15.00-15.45	Vascular Malformations – IR Options
15.45-16.30	Vascular Malformations – Surgical Options
16.30-16.45	The patient perspective: show two of the patient movies (2 x 5min)
16.45-17.30	Vascular Malformations – Medication Options
17.30: End of the day	

Day 4: Thursday 26th September 2024

9h00-11h10: Vascular Anomalies (VASCA) – PART II (2h)	
9.00-10.00	How do we manage vascular anomalies
10.00-10.10	Multidisciplinary clinic + treatment strategy discussion from a Patient perspective
10.10-11.00	Quiz + Clinical based Case discussions
11.00-11.15: Break	
11.15-18.30: Paediatric and Primary Lymphedema (PPL) (6h)	
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
13.15-14.15: Lunch Break	

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 27th September 2024

9.00-16.30: Hereditary Haemorrhagic Telangiectasia (HHT) (6h)	
9.00-9.10	**INTRODUCTION**: VASCERN HHT Video (HHT from VASCERN HHT) (8 min)
9.10-9.45	**PATIENT'S EXPERIENCE**: Medical history and findings
9.45-10.30	**GENETICS**: Genetics pathophysiology
10.30-11.00: Break	
11.00-13.15	**CLINICAL EXPRESSION, NATURAL HISTORY AND TREATMENT:** 1. Nosebleeds 2. Anaemia, Iron Deficiency, Gastrointestinal Tract 3. The lungs (PAVMs) – Stroke, cerebral abscess 4. The liver (HAVMs) 5. HHT in the brain (CAVMs) 6. SMAD4 specifics, JPHT 7. Pregnancy: the most dangerous time for women with HHT 8. Common diseases that can mimic HHT in usual medical practice (other causes of bleeding, breathlessness, etc.) 9. Rare conditions that may be encountered 10. New treatments
13.15-14.15: Lunch Break	

14.15-15.45	**CASE DISCUSSION**: Workshop: Structured initial assessment, clinical management and follow-up of a case
15.45-16.30	**SUMMARY + Q&A SESSION**
16.30: End of the day	

Day 6: Saturday 28th September 2024

9.30-13.30: Final activity on Psychology - role-plays with patients and doctors (4h)	
9.30-12.30	**ROLE PLAYS WITH PATIENTS AND DOCTORS:** • Communicating a diagnosis • Communicating the need for surgery • Managing care post surgery
12.30-13.30	**END OF THE ACTIVITY:** Debriefing of the experience with the participants
13.30: End of the VASCERN Summer School	

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