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VASCERN



VASCERN 2 SUMMER 0 SCHOOL 2 4

Candidate Information Booklet



Erasmus+

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INTRODUCTION TO VASCERN

VASCERN is the European Reference Network (**ERN**) that aims to improve and homogenize the care of patients with rare multisystemic vascular diseases across Europe. These diseases include arterial diseases (from aorta to small arteries), arteriovenous anomalies, venous malformations, lymphatic disorders and neurovascular diseases. These diseases are rare and complex, requiring a multidisciplinary approach to patient care.

VASCERN was established in 2017 and is funded by the European Commission. VASCERN is based at the Hôpital Bichat in Paris (Assistance Publique - Hôpitaux de Paris, APHP) and its coordinator is Guillaume Jondeau, Professor at the University Paris Cité.

VASCERN is composed of six Rare Disease Working Groups (RDWGs), each of which specializes in a particular disease or group of diseases.

- **Hereditary Haemorrhagic Telangiectasia (HHT-WG)**, dealing specifically with HHT.
- **Heritable Thoracic Aortic Disease (HTAD-WG)**, which deals with aortic diseases such as Marfan syndrome or Loeys-Dietz syndrome.
- **Medium-Sized Arteries (MSA-WG)**, which focuses on vascular Ehlers-Danlos syndrome (vEDS).
- **Neurovascular Diseases (NEUROVASC WG)**, dealing with CADASIL and Moyamoya angiopathy.
- **Pediatric and Primary Lymphedema (PPL WG)**, which covers structural or functional disorders of the lymphatic system.
- **Vascular anomalies (VASCA-WG)**, which covers conditions such as capillary malformations, venous malformations and severe/rare infantile haemangiomas.

In addition, a specific subgroup composed exclusively of patient advocates has been created, known as the **European Patient Advocacy Group (ePAG)**.

The members of these RDWGs meet regularly and produce resources for doctors and patients, including educational videos, guidelines, clinical outcome measures, and expert consensus statements. These resources are initially written in English, but most are translated into other languages and used throughout Europe and the world. The goals of VASCERN are therefore to:

- **Improve medical knowledge** by sharing experiences, conducting clinical trials and creating registries.
- **Raise awareness** of the diseases among stakeholders, general practitioners, school doctors and the general public.
- **Improve the quality of family counseling** and reduce care gaps.

VASCERN is a **network in expansion**, as it constantly strives to increase the number of European countries included in the network. Therefore, since its creation, new affiliated partners and full HCP members have been integrated, as well as new patient organizations and advocates from countries not yet represented. In total, **19 European countries** are currently covered by VASCERN, as shown in Figure 1.



Figure 1. Map that shows the European countries covered by VASCERN.

An active policy will be implemented to help new centers from non-represented countries join VASCERN in the future, using the knowledge of patients and their outreach activities, as well as scientific relationships between experts. We also hope to launch communication and outreach campaigns targeting these countries and their rare disease communities.

To keep the network growing, new projects are planned, especially in the area of training and knowledge sharing. These include exchanges of health professionals between centers, the development of a Moodle platform for online training, interaction with future European doctors, etc. In this context, the organization of a summer school for interns and medical students will fit perfectly into our expansion strategy, as it will be a valuable activity to disseminate the objectives of the network to the new generation of doctors in Europe.

VASCERN SUMMER SCHOOL

The **Summer School** is an educational activity organized within VASCERN to train young doctors on rare vascular diseases and to perpetuate the goals of the network to the new generation of healthcare professionals.

The organization of the VASCERN Summer School has received financial support from the **ERASMUS+ Blended Intensive Program (BIP)**. This means that the Summer School will follow a hybrid format, combining short-term physical mobility abroad with a compulsory virtual component.

The online part of the summer school will last for 15 weeks. It will consist of e-learning activities on the different diseases, webinars, workshops on psychology and training on research and genetics. During these virtual sessions, students are able to interact with each other and with the experts of the network to deepen the learning and create professional links for the future. This part will take place before the onsite part and is intended as a theoretical introduction to rare vascular diseases.

The onsite part of the Summer School will last 6 days and is designed to cover the different vascular diseases covered by VASCERN. In the VASCERN Summer School, participants from different universities in Europe will be able to join and follow the courses given by the experts of the network. The objective of the program is quite broad, including

- Medical students (Undergraduate, Master, PhD)
- Interns from various universities in Europe



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We are expecting at least 30 participants, aiming to reach the widest possible European geographical coverage. The VASCERN Summer School will also allow countries that do not have a national plan for rare vascular diseases to be connected to our network and its activities.

Our goal in the search for participants and partner institutions is to target underrepresented countries in addition to those that are already part of our network. This includes countries in Central and Eastern Europe: Romania, Serbia, Latvia, Poland, Estonia, Bulgaria, Czech Republic, Slovakia, Albania, etc.

Our hope is that this program will increase participants' awareness of rare vascular diseases as well as inspire them to become experts of these diseases in the future.

The **online module** of the VASCERN Summer School will last a total of 15 weeks, from February to May, 2024. The **on-site session** of the VASCERN Summer School will take place in Paris from Monday, September 23 to Saturday, September 28, 2024.

HOW TO PARTICIPATE IN THE SUMMER SCHOOL

If you want to learn about rare vascular diseases from a multidisciplinary perspective and you are a medical student (undergraduate, master or PhD level) or an intern at any European university, you are eligible to participate in the VASCERN Summer School. In this section you will find the steps to follow if you want to apply:



End of September – Mid November

- Participants can send their application to erasmus@vascern.eu.
- The documents required are: Updated CV + Letter of Motivation.

Mid November

- Deadline for applications is **November 19, 2023**.
- Applications will be sent to the **selection committee** consisting of 6 VASCERN experts and 1 patient representative.
- The selection committee will review the applications and select the participants.

End of December

- Participants will receive a response regarding the selection process.

January

- Selected participants will contact their universities to fill out the **Learning Agreement** and receive information on how to obtain the **mobility grant**.



ACADEMIC INFORMATION

The structure and organization of the VASCERN Summer School must meet the requirements of the ERASMUS+ Blended Intensive Programs. For academic accreditation, the content provided during the activity (both online module and on-site activity) must be equivalent to 3 ECTS. Therefore, the total duration of the program will be 75 hours, which will be distributed as follows

- Online module: 29h
- Summer School: 40h
- Evaluation: 6h

The program and ECTS equivalence will be reflected in the ERASMUS+ Learning Agreement, which will be signed by the participant, the home institution and the host institution before the start of the exchange. The purpose of the Learning Agreement is to ensure transparent and efficient preparation of the exchange and to ensure that students receive recognition for the activities successfully completed abroad.

The Learning Agreement (provided by the sending university as part of the BIP) will include all the learning outcomes that the student is expected to achieve during the exchange. All parties who sign the Learning Agreement commit themselves to adhere to all agreed arrangements, thereby ensuring that the student will receive recognition of the study completed abroad without any further requirements.

PROGRAM OF VASCERN SUMMER SCHOOL

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) <ul style="list-style-type: none">• 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) <ul style="list-style-type: none">• 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 <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> 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') <ul style="list-style-type: none">• 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: <ol style="list-style-type: none"> 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 specific, 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: <ul style="list-style-type: none"> • 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	

**Please note that the program may be subject to change depending on the availability of the lecturer.*

Evaluation (6h)

A final examination will be held to ensure that the participants of the VASCERN Summer School have assimilated the contents of the program. More information about the modalities of this exam will be provided soon. Regardless of the type of exam (written report, final exam, quiz, etc.), the duration of the evaluation process will be 6 hours, as it includes an estimated time for the student to prepare.

PRACTICAL INFORMATION

The on-site summer school will take place at the Amphithéâtre Chiray of the Hôpital Bichat (Paris). The hospital is located in the 18th arrondissement of the city (46 rue Henri Huchard) and is easily accessible by public transport:

Metro line  **13** at *Porte de Saint-Ouen station*

RATP Bus Lines **21** **237** **341** **Traverse Batignolles Bichat**

Tramway  **T3b** at *Porte de Saint-Ouen station*

VASCERN will provide several options for accommodation near the hospital. The exact address and details of the hotels will be provided later.



CONTACT

If you would like to apply for the VASCERN Summer School and/or have any questions, please do not hesitate to contact us at erasmus@vascern.eu.