8.30-9.00: Welcome by Prof Guillaume Jondeau and brief introduction by all participants (30’)

9.00-9.45: VASCERN Structure & Organisation: State of play 1 (45’)
Presentation of VASCERN & Functioning since March (20’) (Guillaume Jondeau, Marine Hurard)
Feedback, Q&A and discussion (25’)

9.45-10.05: VASCERN Patient Group (ePAG) (20’) including Q&A
ePAG involvement within VASCERN, co-presentation by the Patient Group Chair & EURORDIS (Paolo Federici, Matt Bolz-Johnson)
Q&A

10.05: coffee break
Photo booth

10.20-11.20: VASCERN 1st year Action Plan: State of play 2 (60’)
Objectives & state of play of Work packages (Marine Hurard) & Feedback from the Council (Guillaume Jondeau and WGs Chairs: Julie de Backer, Claire Shovlin, Leema Robert, Miikka Vikkula, Sahar Mansour, Alessandro Pini, Leo Schultze Kool, Paolo Federici) (40’)
Q&A and discussion (20’)

11.20-12.15: Achievements, Challenges & Opportunities for ERNs (55’)
The ERN Policy (Anna Carta, ERN Team, DG SANTE, European Commission) (10’)
The ERN Collaborative platform and the Clinical Patient Management System (Jean-Marie Misztela) (10’)
ERN Board of Member States views (Muriel Eliaszewicz, French representative at the ERN Board of Member States) (10’)
European Joint Programme on Rare Diseases Research: opportunities for ERNs (Daria Julkowska) (10’)
Q&A (15’)


Medical view

Clinical Area of Expertise
Vascular Diseases including rare, low prevalence and complex disorders that affect different types and sizes of vessels:

- Aorta HTAD
- Medium Size Arteries MSA
- Small Arteries / Veins / Lymphatics / Capillaries
  - VASCA
  - HHT
- Lymphedema PPL

and involving Multisystemic consequences and external signs (skeletal, dermatological, eyes, etc.)

1.3 million patients in the EU (under-estimated prevalence)
Rare Diseases to be included in the Future

• **MSA-WG** (now including only vascular Ehlers-Danlos Syndrome):
  – Fibromuscular Dysplasia (FMD)
Structural view

Healthcare Provider Members

Structure

Governance
HCP Members from 11 EU Member States

« Affiliated Members »: not yet developed, awaiting for Board of Member States designation

2018: new ERN Call for Membership, obj: extend to other EU Member States

Members’ role to disseminate to their national networks
Governance

**ASSEMBLY**
- More HCP & PO representatives
- Once a year at Board meetings

**5 RARE DISEASES WORKING GROUPS (RDWG)**
- 1 Chair, 1 Co-chair
- Members
- Virtual monthly meetings

**5 TRANSVERSAL WORKING GROUPS**
- 1 Chair, 1 Co-chair
- Members
- Virtual monthly meetings

**BOARD**
- chaired by NETWORK COORDINATOR
- Strategic Decision-making
- Evaluation, Feedback
- At least once a year

**COUNCIL**
- Operational Decision-making
- Evaluation, Feedback, Reporting
- WG Chairs + Coordinator
- Co-chairs (substitutes)
- Every 4 months or related to needs

**ADVISORY BOARD**
- Consultation and external evaluation
- Scientific Societies & other experts

**OTHER ERNs REPRESENTATIVES**
- (as necessary)

**ePAG (Patient Group)**
- 1 Chair, 5 Co-chairs (1/RDWG)
- Members
- Virtual monthly meetings

**FEEDBACK TO**
- the Council

**REPORTING TO**
- the Council
Inter-ERNs Working Groups

• **Medical:** ERN-Skin & further interERNs cooperation to be developed

• **Inter-ERN WGs:**
  - Monitoring, Assessment & Quality Improvement (Guillaume Jondeau)
  - Ethical & Legal issues (data protection, conflict of interest, informed consent) (Romain Alderweireldt)
  - Research (Xavier Jeunemaître)
  - IT & Data sharing
  - Knowledge generation: Training, education, capacity building, guidelines
  - Cross-border healthcare (organisation, provision)
  - Brexit
What are our 1st year objectives?

10 Work Packages
(March 2017-February 2018)
<table>
<thead>
<tr>
<th>WP</th>
<th>Description</th>
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<tbody>
<tr>
<td>WP1</td>
<td>Sharing of experience: discussion of difficult clinical cases on a secured Clinical Patient Management System (CPMS) by each VASCERN Rare Disease Working Groups</td>
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<tr>
<td>WP2</td>
<td>Definition of patients pathways by each VASCERN Rare Disease Working Groups</td>
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<td>WP3</td>
<td>Creation &amp; Development of a cross-border pathways Mobile Application for IOS &amp; Android</td>
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<td>WP4</td>
<td>Pills of Knowledge</td>
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<td>WP5</td>
<td>Registries: working towards the creation of a VASCERN registry</td>
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<td></td>
<td>- Survey of existing registries and biobanks</td>
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<td>- Minimum dataset</td>
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<td>WP6</td>
<td>Clinical trials</td>
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<td>WP7</td>
<td>Availability of conferences on YouTube</td>
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<td>WP8</td>
<td>Definition of clinical outcomes</td>
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<td>WP9</td>
<td>Writing recommendations</td>
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<tr>
<td></td>
<td>J1: Clinical recommendations</td>
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<td>J2: Do’s and Don’ts factsheets</td>
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<tr>
<td>WP10</td>
<td>Communication</td>
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<tr>
<td></td>
<td>- Website</td>
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<td>- Social Networks</td>
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<td>- Monthly Newsletters</td>
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<td>- Collaborative Platform (internal communication)</td>
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<td>- Translation of material directed to patient care information</td>
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How to reach the goals?

The tools provided
Funding

• **Prior to EU co-funding:** Filière FAVA-Multi (funded by the DGOS, French Ministry of Health): European Development (2016, answer to ERN Call)

• **1st year EU co-funding:**

![Pie chart showing funding distribution for Vascular Diseases (VASCERN).](chart.png)

- EU: 200 K€/year
- DGOS French Ministry of Health: 60 K€
- Filière FAVAmulti: 60 K€
- APHP: 14 K€
• **EU co-funding for:**
  - Manpower: the VASCERN Coordination team
  - Meeting organisation
  - Communication, translation, eHealth tools

• **Virtual communication platforms:**
  - Videoconferences: Webex already used by all WGs
  - ERN Collaborative platform (ECP) for our Members (including documents storage, news, forums, shared agenda, library,...)
  - Clinical Patient Management System (CPMS): to be used soon
    • Ethics: informed consent
Medical knowledge and expertise that travel rather than the patients

HOW WILL ERNS HELP PATIENTS?

Monthly RDWG videoconference meeting

Discussions on Work Packages & Clinical cases

HCPs & Patient Representatives
Our VASCERN project aims to facilitate and improve diagnosis, treatment and care for ALL patients suffering from Rare Multisystemic Vascular Diseases, thus enhancing access to care, and improving quantity and quality of life of these patients. Networking, sharing and spreading our expertise, promoting best practices, guidelines and clinical outcomes, patient-empowerment, improving knowledge through clinical and basic research are among our objectives.

Prof. Guillaume Jondeau, Network Coordinator
eHealth Call (CEF Telecom) for ERNs’ implementation of the CPMS (Clinical Patient Management System)

- VASCERN proposal
  - Identical to all ERNs (interERNs IT WG)
    - to hire 2 IT staff: CPMS Operational Helpdesk
  - Submitted on September 21st, 2017
  - Evaluation excepted by December 2017
  - Decision by Feb 2018. Grant by June 2018
  - 75% EU co-funding: 125000
  - 25% Co-funding APHP Bichat
Communication & Dissemination

http://vascern.eu/
What have we done?

The meetings
HOW ARE WE WORKING?
Face-to-face & virtual videoconference meetings
Collaborative Platform & Website

WG meeting
WGs monthly virtual meetings since March 2017

council meeting
1st meeting face to face in Vilnius, March 2017
Otherwise: virtuals

Board meeting
2017: 1 face to face Board and Assembly meeting on October in Paris
Meetings

• **Council:**
  – 1st in Vilnius, kick-off Council meeting, March 2017
  – 2nd virtual meeting, July 2017,
  – 3rd: follow-up of the VASCERN 1st Annual Seminar & Board meeting – before Dec 2017

• **RDWGs:**
  - **HHT-WG:** 7 meetings (including 2 face-to-face meetings in Dubrovnik)
  - **HTAD-WG:** 7 meetings (including 1 face-to-face meeting during the ESC Congress in Barcelona, August 2017)
  - **MSA-WG:** 5 meetings
  - **PPL-WG:** 4 meetings
  - **VASCA-WG:** 7 meetings

• **Transversal WGs:**
  – **eHealth-WG:** 4 virtual meetings
  – **Registry-WG:** first meeting in , second face-to-face in Paris & Technical task force meetings
  – **Ethics & communication WGs:** advisory, no meeting yet

• **Patient Group (ePAG):** 6 meetings (+ 2 face-to-face meetings, in Vilnius & during the EURORDIS Congress in Budapest)
WG Road Map

WPs Progresses & Milestones will be presented during the session on the state of play of our action plan!
Feedback, Q&A and discussion (25’)