



# **PATIENTS AND THE DIGITAL REVOLUTION**

Development of the VASCERN Mobile APP

## **Claudia Crocione**

ePAG co-chair – HHT WG – VASCERN

# VASCERN –eHealth WG



European  
Reference  
Networks

## VASCERN – Vascular Diseases



### Transversal WG: eHEALTH



ITALY

Chair



Dr. Alessandro PINI

Centro Malattie Rare Cardiologiche – Marfan Clinic

Azienda Socio Sanitaria Territoriale Fatebenefratelli – Sacco

Milan, Italy

# Crossborder Mobile App

## Part 1: The Proposal - May 2017



- A rapid guide to identify the Hospital that can offer the best diagnostic and clinical assistance for each rare disease within VASCERN.
- Very simple to use. Clicking on the rare disease the App reveals the hospitals around you that can offer the right answer to your clinical need.
- Clicking on a single hospital the address, telephone number, email of the selected rare disease centre appears.
- Direct dial option, direct road directions

# VASCERN

## e-Health Transversal WG

### Dataset information to be included



- HCP name
- VASC Specialization
- Hospital Name
- Department
- Complete Address
- City and ZIP code
- Country
- Director/Coordinator
- Telephone Number (Direct)
- FAX Number
- Email
- Opening Time
- Core services
- Other specialist evaluation
- Dedicated Emergency Department (Y/N)
- 24/7 Call Center (Emergency)
- **Patient Association Point**
- Website and/or Social media account

**EXAMPLE**

<b>HCP name</b>	Centro Malattie Rare - MarfanClinic	
<b>VASC Specialization</b>	Marfan Syndrome, Loeys-Dietz Syndrome, Ehlers - Danlos Syndrome, Bicuspid Aorta, Aortic Aneurism Diseases	
<b>Hospital Name</b>	Luigi Sacco Hospital - ASST Fatebenefratelli Sacco	
<b>Department</b>	Cardio-Neuro-Angio Department	
<b>Complete Address</b>	Via GB Grassi, 74	
<b>City ZIPcode</b>	Milan-20157	
<b>Country</b>	Italy	
<b>Coordinartor</b>	Alessandro PINI	
<b>Telephone number (direct)</b>	+39 02 3904 3252 +39 02 3904 2279      +39 02 3904 3044	
<b>FAX number</b>	+39 02 3904 2571	
<b>Email</b>	alessandro.pini@asst-fbf-sacco.it mariangela.panetta@asst-fbf-sacco.it	susan.marelli@asst-fbf-sacco.it argentina.romano@asst-fgf.sacco.it
<b>Opening time</b>	Monday to Friday 07.45-17.00	
<b>Core Services offered</b>	Cardiovascular and Clinical genetic evaluations - Psychologist evaluations - Molecular genetic evaluation	
<b>Other specialistic evaluation offered</b>	Cardiac and Vascular Surgery - Ophtalmology - Pneumology - Orthopaedic - Obstetric and Gynechology - ....	
<b>Emergency Dpt Dedicated</b>	YES	
<b>24/7 Call Center (Emergencies)</b>	+39 348 47 49 487	
<b>Patient Association Point</b>	YES	
<b>Website and or Social Media</b>	www.marfanclinic.it Marfanclinic (Facebook)      Marfan Clinic.Milano(Youtube)	



# ePAG DELEGATES' PROPOSAL



- Dedicated section for Patient Organization contact information in the APP.
- PO section independent from Rare Disease Center

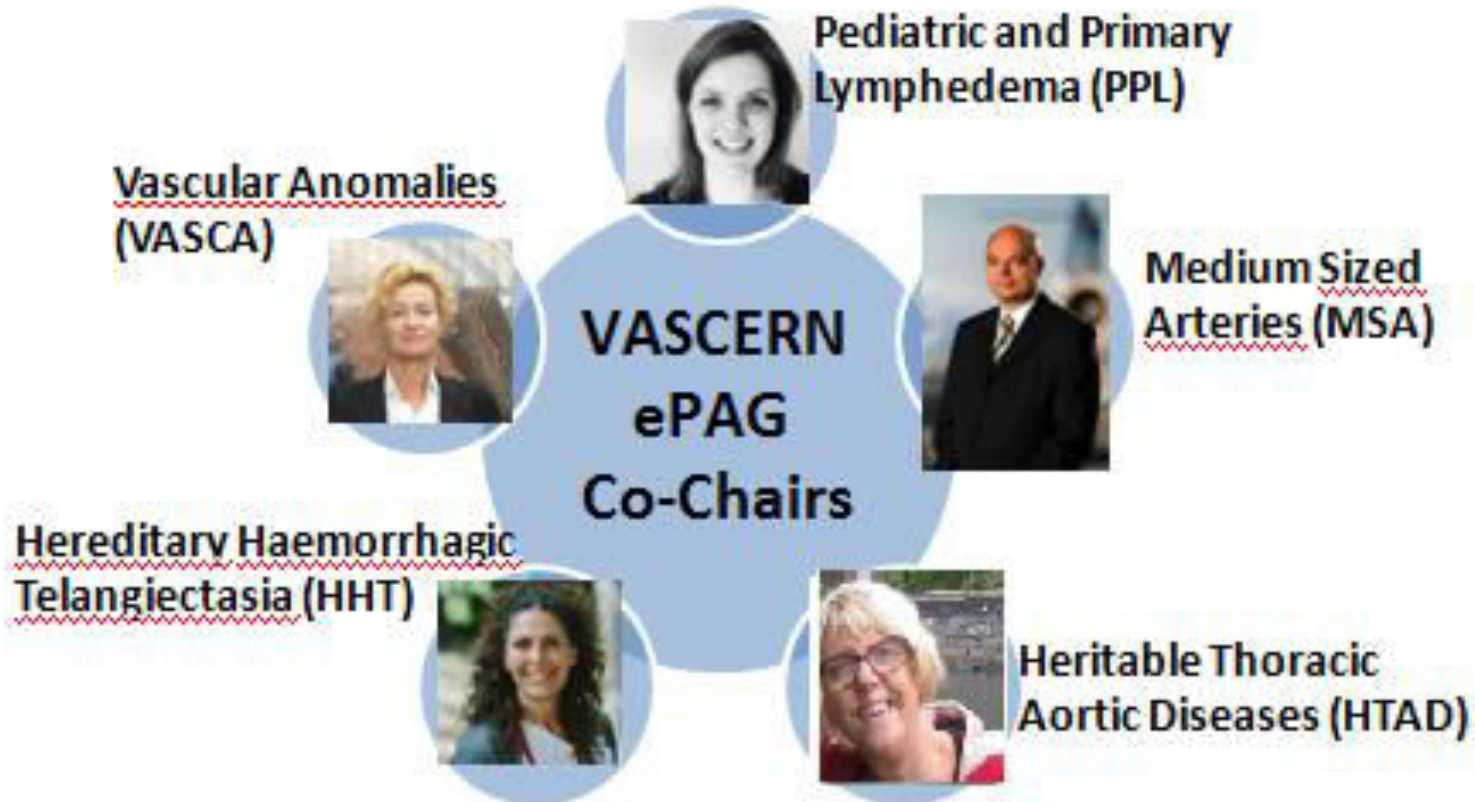
**The proposal IMMEDIATELY was accepted.**

## What this PART 1 tells us



- That although many POs have acquired the awareness of the value of our independent viewpoint we need to constructively work towards equal awareness in our Clinicians.
- That working with Clinicians in the ERNs, POs are offered opportunities, such as this, to point out our independent value.
- That we need delegates that are aware of what patient engagement is and that are aware of the value of patient advocacy on a peer to peer basis.
- Our proposal was easily accepted: **we can be heard.**

# Part II – Actually becoming part of the APP





## Collecting Datasets: Feedback issues

The task of collecting datasets from other ePAGs was easier said than done:

- Lack of responses from ePAGs that had always had low levels of participation
- Difficulties in explaining the usefulness of the APP.
- Many disease group co-chairs still haven't got connections with all patient organizations.

**All added up: lots of work and incomplete results**



## Collecting Datasets: Incomplete contact info

- Collected datasets presented many incomplete fields
- Many do not have a dedicated phone number
- Many are not accessible through social media
- Not all have websites or official emails

**All added up: not all organizations are equally findable.**



## The advantages for Federated POs



The HHT ePAG group benefitted greatly from the existence of the HHT Federation:

- The HHT ePAG co-chair personally knew all the delegates
- Feedback was immediate and accurate
- Trust in the ePAG co-chair favoured adherence to the project
- The Federation had already encouraged many organizations to develop dedicated helplines and social media pages

## What does this tell us?



- ePAGs communities are a growing reality yet PO delegates that are not in the front line don't always grasp the opportunities.
- Some POs on our lists are inactive, we begin to question up to what point we should struggle to get responses.
- Many POs could benefit from federated activities to share knowhow and resources and grow at the same pace of other European realities.
- Do we need to decide what characteristics a PO needs to have to be in the ePAG community?

**All summed up:**

**In a digital world we need to improve:**  
**our findability and reliability**

# A Crossborder Mobile APP for your ERN



The Crossborder Mobile App is a great opportunity.

If you think it would work for your ERN please encourage your ERN coordinator and eHealth WG chair to contact:

*Dr. Alessandro Pini*

*Rare Disease Center - Milan - Italy*  
*alex\_pini@libero.it*



Thank you....



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