



PATIENTS AND THE DIGITAL REVOLUTION

Development of the VASCERN Mobile APP

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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

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

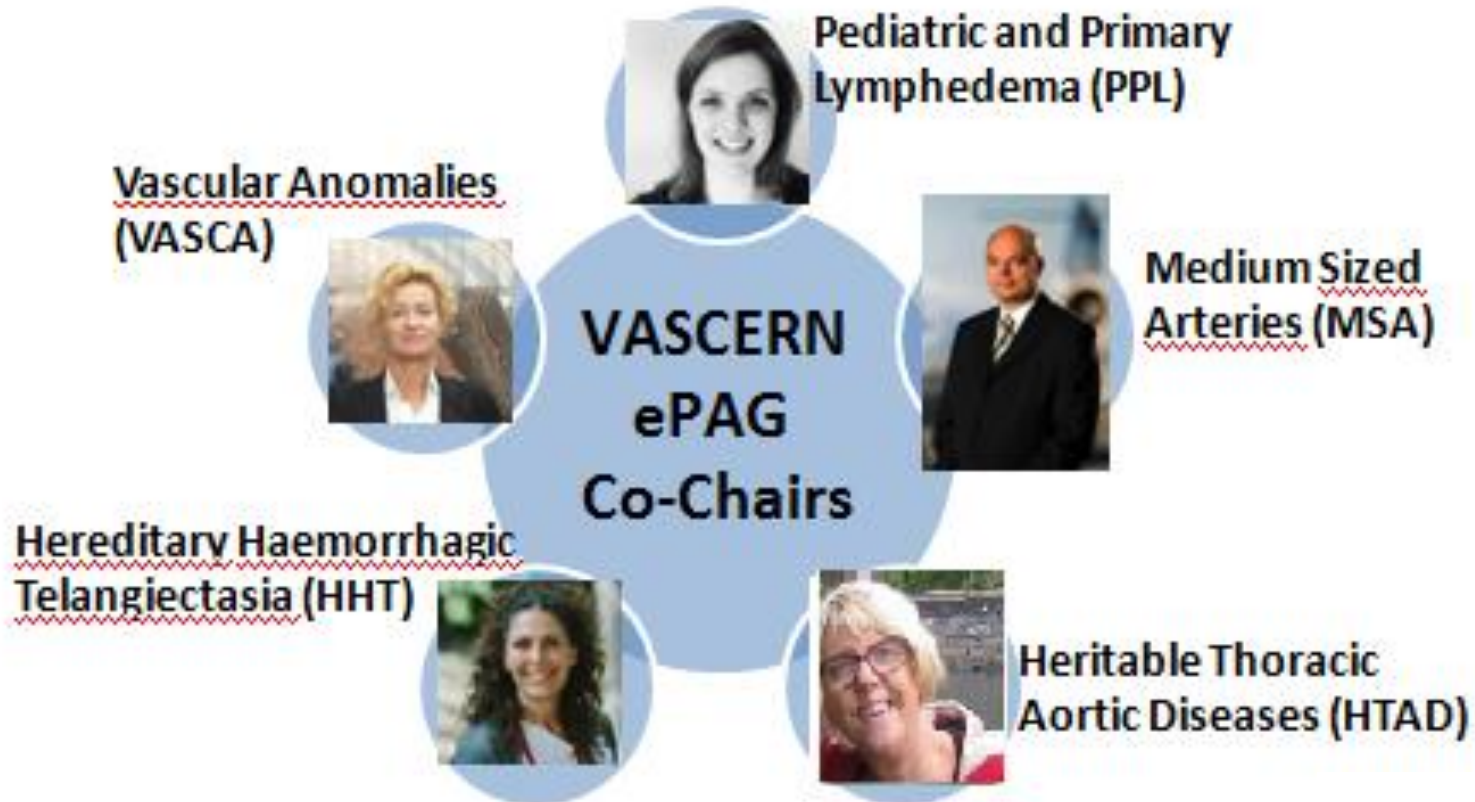
The proposal IMMEDIATELY was accepted.

What this PART 1 tells us



- That many POs have acquired the awareness of our independent viewpoint and value yet we can constructively work towards improving this awareness in the HCP environment.
- That working with Clinicians in the ERNs, is a great opportunity for POs to get the message through and to be of help.
- 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. (Training)
- Our proposal was very easily accepted: **we are 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 PO 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? Can we train those behind to assist them?

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 that we are happy to be a part of.

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

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Rare Disease Center - Milan - Italy

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Thank you....



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