



FONDAZIONE ALESSANDRA BISCEGLIA **A SEARCH ENGINE** FOR VASCULAR ANOMALIES

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INTRODUCTION

Vascular Anomalies are a strange family of diseases, that gathers a high number of "good boys", Hemangiomas, among whom "very bad" conditions, Vascular Malformations , luckily as dangerous as rare, are hidden.

In this situation various physicians, with different types of knowledge, such as General Practitioners, Pediatricians, Dermatologists and others, who do not routinely encounter Vascular Anomalies, can be misled into an incorrect assessment of the problem

OBJECTIVES

In this scenario, the Alessandra Bisceglia ViVa Ale Onlus Foundation, which deals with the study and treatment of Vascular Anomalies, has chosen to support patients and their families by guiding them out of the maze of the disease. The person-centered approach protocol, is intended to support patients finding correct answers and appropriate treatments, reducing financial burdens and minimizing emotional effects, thus improving quality of life.



METHODS

Like a browser in the virtual world, the Alessandra Bisceglia Foundation acts as a search engine, which helps patients with Vascular Anomalies and their families to choose the centers in which to find the correct answers to their needs.

Ale's Rooms

We receive patients and their families in offices called "Ale's Rooms" in memory of Alessandra and to underline the atmosphere of familiarity towards those who contact us.

Two are currently active: one in Lavello (Basilicata) since 2011 and the other in Rome since 2012, where disease experts and psychologists welcome patients, listen to them, clarify the medical situation and help dealing with it.

Patients have the support of the members of our team throughout the entire therapeutic process and, according to their needs, are directed to selected centers with which the Foundation is in contact, or with which it has entered into collaboration agreements. The main collaboration has been stipulated with the University Campus Biomedico of Rome,

where a team of various specialists (surgeon, radiologist, dermatologist ...) including our Scientific Director, plans the therapies of the most complex cases and applies the necessary advanced medical / radiological / surgical procedures.

The Expert Replies

Since 2010 the Foundation has activated an online service which allows askers to make inquiries related to any supposed vascular disease and receive a quick response from a specialist directly in their inbox.

Help Line

Since 2014 the Foundation, in collaboration with the National Center for Rare Diseases of the Istituto Superiore di Sanità, has activated a dedicated telephone line for vascular anomalies, which anyone can dial for information on specialized centers, exemption practices and disability certifications.



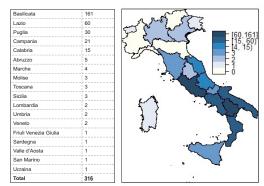
Medical diagnostic, psychological support, orientation and accompaniment services, orientation and accompaniment services, offered by the Foundation, are completely free for patients. Also the centers we choose and propose, depend on the National Health System and, therefore, are free of charge.

In addition to the direct patient care, the Foundation applies a policy, aimed at spreading knowledge, in the field of vascular anomalies

For this purpose, eighteen training courses and eleven conferences earning medical credits have been organized on the subject. We have also published various volumes, including a Clinical Vademecum, a booklet about vascular anomalies, edited under the patronage of the Ministry of Health and distributed free of charge, to doctors who treat our patients and those who request it.

RESULTS (2010-2019)

- Alessandra Foundation, received 426 requests for diagnostic consultancy, divided as follows among our access channels:
- 102 (24%) Expert Replies
- 80 (19%) Help Line
- 244 (57%) direct call to our secretariat.
- 316 initial visits were therefore made and patients diagnosed as: - 90 (28%) vascular malformation - 87 (28%) hemangiomas
- 139 (44%) conditions other than the vascular anomaly.*
- 794 is the total number of accesses to the Ale's rooms for the first visits and follow-ups
- Patients come mainly from central and southern Italy, in particular from Lazio (60) and Basilicata (161), where Ale's Rooms are located.



RStudio Team (2019). RStudio: Integrated Development for R. RStudio, Inc., Boston, MA URL

CONCLUSIONS

Disease	Lavello	Roma	N. of cases	%	44%	
VM	62	28	90	28%		
HEMANGIOMAS	71	16	87	28%		
OTHER THAN THE VASCULAR ANOMALY	74	65	139	44%		
Total	207	104	316	100%	• VM • HENANGIOMAS	OTHER TH

First data to consider is that, against the well known incidence ratio of Hemangiomas vs Vascular Malformations, we have registered almost the same number for each condition. May be that, due to high frequence of Hemangiomas and to the low danger they entail, pediatricians and general practitioners have a better knowledge of the problems and are more confident in their treatment, thus leading families to be less prone to seek a second opinion given by qualified experts.

Meanwhile, the high number of cases that were not labeled as Vascular Anomaly (see results: * red asterisk), such as naevi or other skin lesions, suggests that there is still a lot of confusion in this chapter of diseases.

The number of VMs that we have recruited and that we are currently following-up, demonstrates a high level of patient satisfaction and we believe this is a highly rewarding result, in a field where a complete restitutio ad integrum is, in most cases, difficult to achieve.

Another noteworthy observation is the growing number of patients being sent to us by pediatricians and general practitioners. We firmly believe that this is an important added effect of our presence policy in the medical community.

FINAL THINKING

All rare disease patients share the problem of identifying centers where to be treated. We believe that our tutoring policy, with slight adjustments, can be applied to each of them, with significant benefits in terms of medical results, psychological well-being and relief of social burdens.

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