

## Risorse

### **CENTRI DI RIFERIMENTO REGIONALI:**

Attualmente non esistono centri regionali.

### **ASSOCIAZIONI per questa patologia:**

Associazione Italiana Angiomi Cavernosi (AIAC)  
<http://www.ccmitalia.unito.it/aiac/> <sup>[1]</sup>

### **FORUM su questa patologia:**

Forum <sup>[2]</sup> disponibile nel presente sito.

<http://www.angiomacommunity.org/forum/> <sup>[3]</sup> (ENG)

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Portale Malattie Rare Orpha.net (<http://www.orpha.net> <sup>[4]</sup>)

1: Malattie Rare

1a) "Cavernoma cerebrale <sup>[5]</sup>"

1b) "Cavernoma cerebrale ereditario <sup>[6]</sup>"

2: "Ricerca e sperimentazioni – Progetti di ricerca <sup>[7]</sup>"

3: "Professionisti ed Istituti – Network di progetti di ricerca <sup>[8]</sup>"

### **CENTRI SPECIALIZZATI PER LA DIAGNOSI E IL TRATTAMENTO DELLE CCM**

Diagnosi clinica <sup>[9]</sup>

Diagnosi genetica <sup>[10]</sup>

## **ALTRE ASSOCIAZIONI PER LE MALFORMAZIONI VASCOLARI:**

ILA – Associazione Italiana Angiodisplasie ed Emangiomi Infantili  
<http://www.angiodisplasie.org/index.php> [11]

## **ASSOCIAZIONI ED ORGANIZZAZIONI INTERNAZIONALI:**

Angioma Alliance (USA) – <http://www.angiomaalliance.org/> [12]

Cavernoma Alliance UK (Gran Bretagna) – <http://www.cavernoma.org.uk/home.html> [13]

Angioma Alliance Canada - <http://ccm.angiomaalliance.ca/> [14]

ACC - Association sur les Cavernomes Cérébraux (Francia) – <http://asso.orpha.net/ACC/cgi-bin/> [15]

National Organization for Rare Disorders (NORD – USA) – <http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/620/viewAbstract> [16]

National Institute of Neurological Disorders and Stroke (NINDS – USA) – [http://www.ninds.nih.gov/disorders/cavernous\\_malformation/cavernous\\_malformation.htm](http://www.ninds.nih.gov/disorders/cavernous_malformation/cavernous_malformation.htm) [17]

Orphanet [18]- Il portale delle malattie rare e dei farmaci orfani - Laboratori di diagnosi molecolare delle malformazioni cavernose cerebrali

## **ALTRE RISORSE:**

Genetics Home Reference (USA) – Guida alla comprensione dei disordini genetici [19]

OMIM (Online Mendelian Inheritance in Man) – Catalogo dei disordini genetic [20]

PubMed – Letteratura recente [21]

Ability Channel [22]: la prima web tv dedicata interamente al mondo della disabilità

Le Malattie Rare. info [23]: il portale informativo sulle malattie rare

Health Around Me [24]: il portale social della sanità italiana

**Lingua**  
Italiano

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**Links**

- [1] <http://www.ccmitalia.unito.it/aiac/>
- [2] [http://www.ccmitalia.unito.it/index.php?option=com\\_kunena&view=listcat&catid=0&func=listcat&](http://www.ccmitalia.unito.it/index.php?option=com_kunena&view=listcat&catid=0&func=listcat&)
- [3] <http://www.angiomacommunity.org/forum/>
- [4] <http://www.orpha.net/>
- [5] [http://www.orpha.net/consor/cgi-bin/Disease\\_Search\\_Simple.php?Ing=IT&type\\_list=Other\\_Websites&LnkId=1072&Typ=Pat](http://www.orpha.net/consor/cgi-bin/Disease_Search_Simple.php?Ing=IT&type_list=Other_Websites&LnkId=1072&Typ=Pat)
- [6] [http://www.orpha.net/consor/cgi-bin/Disease\\_Search\\_Simple.php?Ing=IT&type\\_list=Other\\_Websites&LnkId=18935&Typ=Pat](http://www.orpha.net/consor/cgi-bin/Disease_Search_Simple.php?Ing=IT&type_list=Other_Websites&LnkId=18935&Typ=Pat)
- [7] [http://www.orpha.net/consor/cgi-bin/ResearchTrials\\_ResearchProjects.php?Ing=IT&type\\_list=researchtrials\\_search\\_simple\\_shd&data\\_id=](http://www.orpha.net/consor/cgi-bin/ResearchTrials_ResearchProjects.php?Ing=IT&type_list=researchtrials_search_simple_shd&data_id=)
- [8] [http://www.orpha.net/consor/cgi-bin/Directory\\_Professionals\\_Simple.php?Ing=IT&LnkId=34095&Typ=Prs&ActType=Net](http://www.orpha.net/consor/cgi-bin/Directory_Professionals_Simple.php?Ing=IT&LnkId=34095&Typ=Prs&ActType=Net)
- [9] [http://www.ccmitalia.unito.it/aiac/index.php?option=com\\_content&view=article&id=29&Itemid=26](http://www.ccmitalia.unito.it/aiac/index.php?option=com_content&view=article&id=29&Itemid=26)
- [10] [http://www.ccmitalia.unito.it/aiac/index.php?option=com\\_content&view=article&id=30&Itemid=28](http://www.ccmitalia.unito.it/aiac/index.php?option=com_content&view=article&id=30&Itemid=28)
- [11] <http://www.angiodisplasie.org/index.php>
- [12] <http://www.angiomaalliance.org/>
- [13] <http://www.cavernoma.org.uk/home.html>
- [14] <http://ccm.angiomaalliance.ca/>
- [15] <http://asso.orpha.net/ACC/cgi-bin/>
- [16] <http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/620/viewAbstract>
- [17] [http://www.ninds.nih.gov/disorders/cavernous\\_malformation/cavernous\\_malformation.htm](http://www.ninds.nih.gov/disorders/cavernous_malformation/cavernous_malformation.htm)
- [18] [http://www.orpha.net/consor/cgi-bin/ClinicalLabs\\_Search.php?Ing=IT&type\\_list=clinicalLabs\\_search\\_simple\\_shd&data\\_id=18935&Ma](http://www.orpha.net/consor/cgi-bin/ClinicalLabs_Search.php?Ing=IT&type_list=clinicalLabs_search_simple_shd&data_id=18935&Ma)  
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cavernosa-  
cerebrale&ClinicalLabs\_ClinicalLabs\_Search\_diseaseType=Pat&ClinicalLabs\_ClinicalLabs\_Search\_count
- [19] <http://ghr.nlm.nih.gov/condition/cerebral-cavernous-malformation>
- [20] <http://omim.org/entry/116860>
- [21] [http://www.ncbi.nlm.nih.gov/pubmed?term=\(cerebral+cavernous+malformation%5bTIAB%5d\)+AND+english%5bla%](http://www.ncbi.nlm.nih.gov/pubmed?term=(cerebral+cavernous+malformation%5bTIAB%5d)+AND+english%5bla%)
- [22] <http://www.abilitychannel.tv/>
- [23] <http://www.lemalattierare.info/>
- [24] <http://www.healtharoundme.com/Home.aspx>