CCM Italia

2015 has been a very active year for both the CCM Italia research network and the Associazione Italiana Angiomi Cavernosi (AIAC) patient organization.

CCM Italia has further expanded and strengthened the cooperative network among clinical and basic research centers in Italy through the participation of new Units, including major Centers of Excellence in cerebrovascular research and healthcare, such as the C. Mondino National Institute of Neurology in Pavia and the Neuromed Mediterranean Neurological Institute in Pozzilli, Isernia.

To date, the CCM Italia cooperative networking effort has produced a large framework for multidisciplinary and integrated research approaches. This has resulted in novel insights into the understanding of CCM disease pathogenesis and treatment (Marchi et al., 2015 EMBO Mol Med; Marchi et al., 2016 Rare Diseases), and the identification of factors that may modify the range of phenotypic features, determining the large interindividual variability in disease severity (Choquet et al., 2016, Free Radic Biol Med).

AIAC has significantly contributed to provide patients and families with access to current information about CCM disease and leading clinical centers with renowned expertise in cerebrovascular research and comprehensive care delivery, offering support services. It has also helped spread knowledge and raise awareness of CCM disease among Italias people and healthcare institutions through various activities, including comprehensive educational initiatives and the participation to popular regional and national radio and TV programs.

Many CCM patients have received major psychological benefits from the AIAC support, including the possibility to share their clinical stories and interact with people who can listen to them and understand their feelings, offering help to face the disease without feeling alone. One example of this is a letter of a 30-year-old girl from Sicily, stating as follow: “I wished to work, study, dance. I love dancing but I could not and I cannot realize my dreams […] I still hope to be able to realize my dreams: it would be enough if it just one of them can come true.” (See the full text at the Clinical Stories section in the CCM Italia website).

While providing some benefit to patients, such letters constitute strong stimuli and deep motivational input for researchers, who feel the duty of carrying out the best research efforts focused on changing the course of CCM disease in order to provide real and effective help to those who need it. Surely, this achievement would be more gratifying and rewarding than any publication of outstanding and prestigious academic value in renowned journals.

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For more information, please visit the CCM Italia website: www.ccmitalia.unito.it.

References:
1. Micieli G. et al., Cerebrovascular diseases at the C. Mondino National Institute of Neurology: from Ottorino Rossi to the present day. Funct Neurrol. 2011; 26(2):87-95.