International Alliance of ALS/MND Associations

Networking: importance and results of cooperation

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ASSOCIAZIONE ITALIANA
SCLEROSI LATERALE AMIOTROFICA

18th Annual Meeting - JW Marriott, Grand Lakes, Orlando - 8 & 9 December 2010

Networking: importance and results of cooperation

- During last years AISLA has done an intensive activity of development for Italian PALS, both about research and care and during last meetings we have shared our experience with all other Associations members of the Alliance.

Networking: importance and results of cooperation

We have realized that concrete cooperation with other realities operating in our country is a great and really powerful instrument

Networking: importance and results of cooperation

NEuroMuscular Omnicentre (NEMO)

FONDAZIONE SERENA ONLUS

UILDM

AISLA

FAMIGLIE SMA

TELETHON

NIGUARDA

REGIONE LOMBARDIA

Funding Members

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ASSOCIAZIONE ITALIANA
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FONDAZIONE VIALLI E MAURO
PER LA RICERCA E LO SPORT
ONLUS

AriSLA
AGENZIA DI RICERCA PER LA
SCLEROSI LATERALE AMIOTROFICA

fondazione cariplo

Annual Budget: 1,5 ml Euro

20° TeleThon
insieme dal 1990

Networking: importance and results of cooperation

We have realized that concrete cooperation with other realities operating in our country is a great and really powerful instrument:

- NEMO
- ARISLA

These are concrete results but represent also an important starting point.

Networking: importance and results of cooperation

This attitude towards networking has brought us to push Italian Government, in particular Minister of Health, to establish a technical **very operative group** (so called "*Consulta per le Malattie Neuromuscolari*"), sharing experiences and needs of all actors (patient associations, physicians, institutional representatives, etc) involved in neuromuscular diseases with similar difficult path of diagnosis and care.

Networking: importance and results of cooperation

The “*Consulta per le Malattie Neuromuscolari*” was established by ministerial decree on 27th February 2009.

The principal objectives of the “Consulta” were:

❿ to promote the quality of care and the research for patients with severe neurological disorders, such as ALS, Muscular Dystrophy, Spinal Muscle Atrophy, Multiple Sclerosis with high level of disability, and Locked-in Syndrome.

❿ to produce a final document with a sort of guidelines to be applied by everybody and to guarantee all legislative supports equally in all Regions in Italy without any kind of disparity of treatment.

Networking: importance and results of cooperation

Consulta Ministeriale sulle Malattie NeuroMuscolari

President: Mario MELAZZINI - *Associazione Italiana Sclerosi Laterale Amiotrofica AISLA ONLUS*

Patient associations

Roberto BALDINI
- Associazione per lo Studio delle Atrofie Muscolari Spinali Infantili - ASAMSI Onlus

Pietro Vittorio BARBIERI
- Presidente Nazionale FISH - Federazione Italiana per il Superamento Handicap

Mario Alberto BATTAGLIA - *AISM-FISM Onlus Associazione Italiana Sclerosi Multipla e Fondazione Italiana Sclerosi Multipla*

Alberto FONTANA
- Unione Italiana lotta alla Distrofia Muscolare UILDM Onlus

Luca GENOVESE
- PARENT PROJECT Onlus Genitori contro la Distrofia Muscolare Duchenne e Becker

Raffaele GORETTI - *Presidente Federazione Associazioni Italiane Paratetraplegici*

Renato POCATERRA - *FAMIGLIE SMA Genitori per la Ricerca sulle Atrofie Muscolari Spinali*

Physicians

Adriano CHIO' - *Dipartimento neuroscienze Azienda Sanitaria Ospedaliera Molinette - Torino*

Massimo CORBO
- Centro Clinico NEMO, Fondazione Serena Onlus, Milano

Gian Luigi LENZI
- Professore Ordinario di Clinica Neurologica - Università La Sapienza - Roma

Representatives of Ministry of Health

Filippo PALUMBO - *Direttore Generale della Direzione della programmazione sanitaria, dei livelli essenziali di assistenza e dei principi etici di sistema (DGPROG)*

Massimo CASCIELLO - *Direzione Generale della Ricerca Scientifica e Tecnologica (DGRST)*

Guido DITTA - *Direttore dell'ufficio 7 Promozione salute e integrazione socio-sanitaria - Direzione della Prevenzione Sanitaria (DGPREV)*

Representatives of Regions

Five working groups

- DIAGNOSIS
- RESEARCH
- DISEASE REGISTRY
- REHABILITATION
- INTEGRATED CARE PATHWAY

Working group: DIAGNOSIS

Objectives

- to determine an operating procedures to reduce the delay for the attribution of the invalidity insurance
- to determine the guidelines for medico-legal evaluation of the disability for the neurological disorder with higher level of complexity

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Working group: RESEARCH

Topics:

❿ Network and model of care

❿ Clinical Trials

❿ Funding

❿ Scientific divulgation

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Working group: Disease Registry

Topic: Analisys of the epidemiological data concerning the neurological disorder with higher level of complexity

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Questionnaire for quality of care

Study population: 540 patients including ALS, MD, SMA and MS.

Items analyzed:

❿ *Demographic data*

❿ *Clinical data* (type, disability degree, co-morbidity, etc.).

❿ *Degree of Satisfaction of the following service* (Health services, education, social services, etc.).

❿ *Hopes and suggestions*

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Working group: Disease Registry

Questionnaire for quality of care

Results:

- in the majority of patients the care is dependent on the family with poor support from the social and health services.
- in the majority of the cases palliative care and psychological support are fee-pay services.
- the 50% of patients conflicted with bureaucratic difficulties, experienced poor attention towards problems related to disability and met architectural barriers.
- Patients and caregivers reported a negative experience of the public psychological support services

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Working group: REHABILITATION

Multidisciplinary approach

Early and global care of patients for an adeguate rehabilitative approach

Definition of the “Integrated and Personalized Rehabilitation Project” that includes programs, objectives, and timing of the rehabilitative treatment, considering the different areas of intervention

Identification in all Regions of first and second level Referral Centres devoted to Neuromuscular Disorders

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Working Group: INTEGRATED CARE PATHWAY

Continuous Care

Integration of interventions dedicated to patients

Coordination of the services according to network model and global care

Identification in all Regions of first and second level Referral Centres devoted to Neuromuscular Disorders

Establishment of the territorial multidisciplinary team

Etablishment of the case manager

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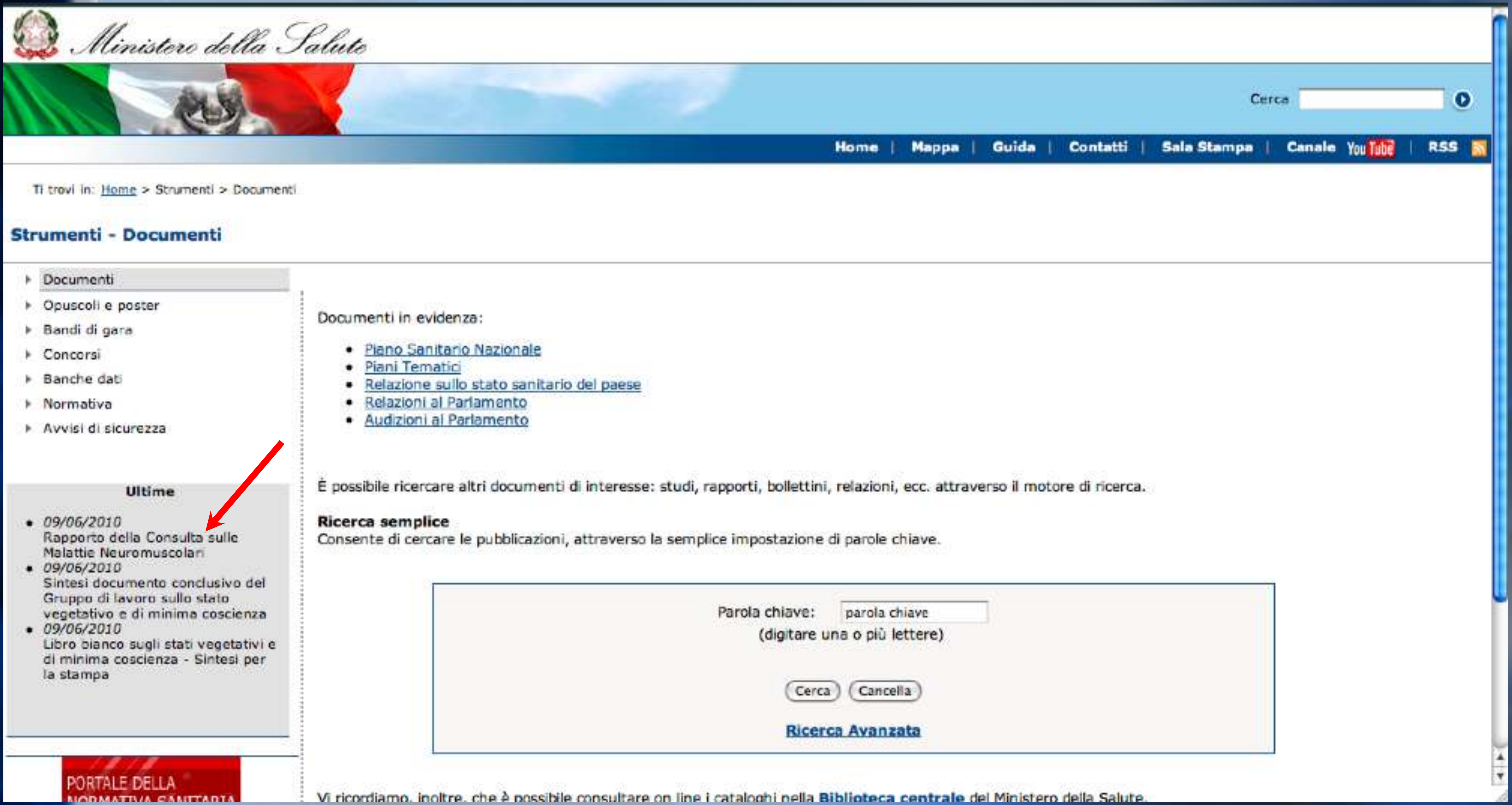

Ti trovi in: Home > Strumenti > Documenti

Strumenti - Documenti

Documenti in evidenza:

- Piano Sanitario Nazionale
- Piani Tematici
- Relazione sullo stato sanitario del paese
- Relazioni al Parlamento
- Audizioni al Parlamento

È possibile ricercare altri documenti di interesse: studi, rapporti, bollettini, relazioni, ecc. attraverso il motore di ricerca.

Ricerca semplice
Consente di cercare le pubblicazioni, attraverso la semplice impostazione di parole chiave.

Parola chiave: parola chiave
(digitare una o più lettere)

Cerca | Cancella

Ricerca Avanzata

Ultime

- *09/06/2010*
  Rapporto della Consulta sulle Malattie Neuromuscolari
- *09/06/2010*
  Sintesi documento conclusivo del Gruppo di lavoro sullo stato vegetativo e di minima coscienza
- *09/06/2010*
  Libro bianco sugli stati vegetativi e di minima coscienza - Sintesi per la stampa

Vi ricordiamo, inoltre, che è possibile consultare on line i cataloghi nella **Biblioteca centrale** del Ministero della Salute.

http://www.salute.gov.it/imgs/C_17_pubblicazioni_1278_allegato.pdf

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