

La Malattia di Huntington.. A cura dell' Associazione Italiana Còrea di Huntington (Milano-Roma-Napoli)

Abruzzo G., Albanese A., Bandettini M., Bentivoglio A.R., De Michele G., Di Maio L., Frontali M., Jacopini G., Raja M., Soleti F., Soliveri P., Zinzi P. (2008).

In July 2007, upon request of the Italian Association for Huntington's Chorea (A.I.C.H-Rome and A.I.C.H-Milan), the research group CNR and UCSC Policlinico Gemelli of Rome organized a multidisciplinary panel of Italian experts about Huntington Disease (HD) with the main task of providing recommendations for the best management of patients. The panel has produced a consensus document that address HD patients' main needs, combining together scientific information and long lasting clinical experience in relation to the care of patients and their families.

Handling these patients involves covering multiple aspects, such as: making the diagnosis and communicating it, drug therapies and paramedical treatments, nutrition and dietary supplements, genetic risk and genetic testing protocol, major risk factors of morbidity and mortality, palliative and end-of-life care, non medical support (in terms of psychological and legal assistance and welfare facilities), indications for referral.

The document, written in Italian, analyzes and explains all the different key points. It also offers for each aspect practical suggestions by translating complicated research findings in to simple recommendations for clinical care. The general aim is to reduce the delivery of inappropriate care and to introduce new knowledge into clinical practice.

In detail, first of all, the consensus document is aimed at an advocacy function by drawing attention to unmet patients' needs and to neglected areas of public health; a second aim is to evidence the inequities of care and to set standards of HD patients' assistance; the third goal is promoting medical professionals knowledge of international research achievements in this field and involving them to debate the real meaning of *quality of care*.

The document has been printed (10.000 copies) and, starting May 2008, introduced in the course of three main educational events for neurologists. At present we are disseminating the document to the relevant audience such as neurologists, geriatrists, outpatient clinics involved with movement disorders.

A.I.C.H-Rome and A.I.C.H-Milan will also be active in disseminating the document to family doctors involved with HD patients through patients' families. A.I.C.H-Rome website will also play a relevant informative role.

Educational events May–June 2008

172 neurologists attended 3 educational events (Milan, Naples, and Rome). Their evaluation of the meeting was very positive; the majority considered the information received as *"effective in driving me to change some aspects in my clinical practice"*.

This positive and prompt reaction by neurologists seems to promise the diffusion of better standards of care of HD patients. The main challenge will be the implementation of the document in an optimal manner into clinical practice. In twelve months it is planned to assess the impact of the document in clinical practice through meaningful and measurable outcomes.

The expert panel led by **Dr. Anna Rita Bentivoglio** includes:

Giovanni Abbruzzese, Monica Bandettini (Dipartimento di Neuroscienze, Oftalmologia e Genetica - Sezione di Neurologia, Università di Genova)

Alberto Albanese (Fondazione I.R.C.C.S. Istituto Neurologico "Carlo Besta" e Università Cattolica, Milano)

Paola Soliveri (Fondazione I.R.C.C.S. Istituto Neurologico "Carlo Besta", Milano)

Anna Rita Bentivoglio, Francesco Soleti (Dipartimento di Neuroscienze, Policlinico "Agostino Gemelli" Università Cattolica del Sacro Cuore, Roma)

Giuseppe De Michele, Elena Salvatore, Luigi Di Maio (Dipartimento di Scienze Neurologiche, Università degli Studi di Napoli "Federico II")

Marina Frontali (Istituto di Neurobiologia e Medicina Molecolare, C.N.R., Roma)

Michele Raja (Servizio Psichiatrico, Ospedale S. Spirito, Roma)

Gioia Jacopini, Paola Zinzi (Istituto di Scienze e Tecnologie della Cognizione, C.N.R., Roma)

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