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Assistance Publique Hôpitaux de Paris

JA2015 - GPSD [705038]

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PROGRAMME TITLE: Second Programme of Community action in the Field of Health 2008-2013

PROGRAMME PRIORITY: -

CALL: Promote Health (Hp-2010)

TOPIC: PROMOTE HEALTH (HP-2010)

EC CONTRIBUTION: 167160 EUR

KEYWORDS: Diagnostic, Health system, Patients registries, Quality evaluation, Rare diseases and disorders

PORTFOLIO: Interest groups, Rare diseases

Mission and vision of the operating grant holder

EuroWilson (EW) mission is to improve quality of care and access to multi-disciplinary expertise for EU patients with Wilson's disease (WD). From 2004-2008 EW (LSHM CT2004 503430), has achieved:

- An active patient registry
- Interaction between clinicians and an expert validation committee
- External molecular quality network
- A DVD in the neurological evaluation
- Transferring knowledge by contribution to the public consultation papers and participation in policy conferences
- organisation of a European patient meeting during the Eurordis conference

EW's goals include maintaining and enhancing this network; the French centre for WD serves as a network model. The network will include all stakeholders involved in patient care: medical, scientific para-medical, EU authorities and patients' associations. EW will:

- Promote exchange between participants
- Provide up-to-date disease information on its website (eurowilson.org) and Orphanet
- Develop and publish evidence based clinical guidelines
- Enhance the registry to provide epidemiological data, outcome indicators, country comparisons and to facilitate collaborative research and public health projects
- Support patients and patient associations in the EU

Strategic objectives and specific activities

The general objective of EW is to develop the EU WD multi-disciplinary network and its registry and ultimately to provide EU patients and their families with up-to-date information, optimised management and equal access to expert advice, diagnosis and care.

Objective 1: improve information and services to patients, health professionals and general public

- Development and dissemination online of up-to-date information and educational documents for patients and families in their own language, information for health professionals including social workers and nurses
- Develop a ♦bibliographic journal watch♦ with two levels of information: interpretation for the lay public and patients and interpretation for scientific audience
- Help set up EU patient meetings, on average once every two years with the aim to transfer experience between different national associations. Torben Gronnebaek and Eurordis will have a strong role in this activity

Objective 2: Increase knowledge of the disease

- Continue information sharing between different WD expertise. Since its beginning, EW has successfully produced a neurology scoring system, a hepatic scoring system, a laboratory external quality assessment programme, several publications and information for children, parents and adult patients in patients own language
- Continue the annual network meetings
- Continue to enter newly diagnosed patients in countries that have resources to do so and follow-up into the registry, analysis of indicators to show evolution of care and impact of rare disease plans. The feasibility of this has been determined by the success of the French contribution to the EW database which currently has a cohort of 285 patients.

Objective 3: Improve access to diagnosis, treatment and high-quality health care

- Encourage new labs to participate to EMQN mutation quality assay
- Develop European guidelines on the management of the disease
- Evaluate current status of the availability of WD diagnostic tests and expert clinical care in Europe
- Work with the MS national plans or strategies for rare disease with the objective to work with one database on WD which provides policy makers with information necessary in resource decisions. Long-term sustainability is one of our aims within these national plans

Expected outcomes

Objectives and methods:

Objective 1: improve information and services to patients, and HCP`s; The lead of activities related to objective 1 is T.Gronnebaek, patient rep & director of Eurordis

- ◆ Provide information on EU centres with expertise in WD on www.eurowilson.org
- ◆ Determine needs and expectations of patients, families and associations through a survey in collaboration with Eurordis
- ◆ Disseminate to patient organisations
- ◆ Develop and disseminate educational documents adapted to the needs of psychologists, social workers, physiotherapist, speech therapists and nurses.
- ◆ Learn from the Danish patient association and their role when new diagnosis are announced to patients or parents

Objective 2: continue to collect data in the registry and increase knowledge

- ◆ The EW database will be maintained and enhanced by inclusion of new cases and collection of follow-up data
- ◆ The interface between the EU database and the French CNR has been successful; its applicability will be explored in other countries i.e. developing multi-disciplinary teams working with the database
- ◆ Registry data will be produced on: treatments being used and different clinical scenarios; doses used; changes of Rx and reasons for change; outcomes will provide data on drug efficacy, side effects and compliance
- ◆ Quality issues to be examined are: completeness of family screening; indicators of quality diagnosis (symptom-diagnosis interval), treatment (adherence to guidelines) and outcome.

Objective 3: improve patient access to diagnosis, treatment and high-quality care

- ◆ A yearly network meeting to improve awareness, knowledge and quality of care
- ◆ Recruitment of clinicians from under-represented countries,
- ◆ encourage the involvement of professionals allied to medicine and patient representatives
- ◆ Review of difficult cases eg by transmission of MRI images, liver biopsy slides, or neurological video
- ◆ encourage participation to the WD EMQN scheme
- ◆ Survey to establish the availability of different diagnostic tests and clinical care in Europe: hepatic copper assay, mutation and access to multi-disciplinary care and treatment

Objective 4: develop guidelines

- ◆ Guidelines on the investigation and management of WD patients including psychological and social aspects. They will be based on a critical review of the literature and expert opinion. An expert group will share and translate national protocols already used and validated.

Objective 5: develop a journal watch

- ◆ A review of recent publications relevant to WD will be produced thrice yearly. Sub-editors will be asked to review their fields. Two levels will be developed: one professional and one easy to understand for lay people and patients. The reviews will be emailed and produced on-line.

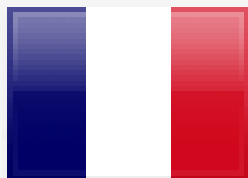
EB Members lead the different tasks. A part-time registry manager will work with Prof Tanner to validate new cases, give feed-back, analyse data and produce reports. The programme manager based in Lariboisiere will have responsibility for day-to-day running in collaboration with the CNR Wilson for writing the reports

Expected outcomes: Knowledge will be improved concerning current care protocols, services provided and outcomes. Recommendations will be given to optimise patient care. Patients and HCPs will get access to up-to-date information on WD in their own language. QoI of patients and families should be improved as they have more efficient diagnosis, care and information.

Target groups: Experts will be able to exchange information, have access to a registry for patient follow-up, patients will benefit from access to improved care, HCPs will have access to information and guidelines and could share their experiences. Health authorities will be aware of the availability of the access to diagnostic test and to expert clinical care in Europe.

The registry has ethical approval. Network members are involved with their national patient organisations. EW will apply with the Eurordis guidelines for collaboration with ERNs

COORDINATOR



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PARTNERS

No partners related to the current project

D03 - Newsletters

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

D01 - Bibliographic journal watch (EN)

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

http://azorina.cc.cec.eu.int:8082/publications/20103201/20103201-d01-01-ot-h-en-ps_binder.pdf

D02 - Networking meeting (EN)

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

http://azorina.cc.cec.eu.int:8082/publications/20103201/20103201-d02-01-ot-h-en-ps_binder.pdf

D04 - guidelines available (EN)

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

<http://azorina.cc.cec.eu.int:8082/publications/20103201/20103201-d04-00-ot-h-en-ps.pdf>

D05-01 - 2011 financial report (EN)

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

<http://azorina.cc.cec.eu.int:8082/publications/20103201/20103201-d05-01-ot-h-en-is.pdf>

D05-02 - 2011 financial report (EN)

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

<http://azorina.cc.cec.eu.int:8082/publications/20103201/20103201-d05-02-ot-h-en-ps.pdf>

D06 - 2011 activity report (EN)

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

http://azorina.cc.cec.eu.int:8082/publications/20103201/20103201-d06-01-ot-h-en-ps_binder.pdf

D07 - 2011 evaluation report (EN)

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

http://azorina.cc.cec.eu.int:8082/publications/20103201/20103201-d07-01-ot-h-en-ps_binder.pdf

D08 - patient survey

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011

http://azorina.cc.cec.eu.int:8082/publications/20103201/20103201-d08-01-ot-h-de-ps_binder_all.pdf

D09 - Survey to WD centres and partners

Assistance publique des hôpitaux de Paris

Assistance Publique Hôpitaux de Paris (AP-HP-Wilson FY2011)

Published on: 01/01/2011