Project summary
Clinical database
EuroWilson collaborators
Austria
Belgium
Croatia
Czech Republic
Denmark
France
Germany
Greece
Hungary
India
Italy
Netherlands
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Denmark

University Hospital, Copenhagen

Contacts

Pædiatric hepatology

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Paediatric centre for liver transplantation and liver disease. Coorporate with Peter Ott (Aarhus University Hospital), who takes care of the national Wilson disease register.

http://www.rigshospitalet.dk/menu/

University Hospital, Aarhus

Contacts

Hepatology

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peterott@rm.dk

Aarhus University Hospital is the second largest university hospital in Denmark. According to a desicion from the National Board of health, Treatment of Wilson's Disease in Denmark is centralized to Medical Department V. The centre takes care of all known WD patients in Denmark.

Patient Organisation

The Danish Association of Wilson Disease

Contacts

info@wilsons.dk

Descritpion of the organisation :
The Danish Wilson's Disease association is an all volunteer organization. They do not receive financial support from pharmaceutical or biotech companies. Once a year it is possible for some organizations to apply for a sum of money from a pool shared out by the Ministry for social affairs. The money is mainly used for young people < 25 of years and their parents when they anticipate in our family-weekend.
Numbers of members are at present time 38, of whom 14 members are patients

Main object acc. to the rules:
- To support and inform patients and their relations, that they by time will get a sufficient and normal life
- Contribute to insure high quality in organization of diagnosis, treatment, research and accumulation of experience
- The experiences of the patients have to be involved in the treatment.
- Keep up with the research in the disease, and if possible support to fx registrars anticipations in conferences.
- Cooperate with relevant associations and organs in Denmark and abroad.
- Guidance on establishing similar associations in Denmark and abroad.

Activities:

- Maintains a membership list which includes all the members.
- Maintain a list with « contacts » in each of the five regions in Denmark. Moreover we have « contacts » for parents, young people and for people having trouble understanding and speaking Danish.
- 3 to 4 times a year INFO is distributed, which tells about the activities of the members of the Board and internal and external occasions.
- Mainly we hold an annual meeting as family-weekend with special contributions. Moreover we have some arrangement for our young members.

Outreach:

- Provides relevant information (pamphlet) for professionals to heighten awareness of the disease
- Distributes pamphlets to doctors for distribution to patients and their families
- If wanted by a member we inform about WD at the place of work or at school.

http://www.wilsons.dk