



France

The National Reference Centre for Wilson's disease, Paris

Contacts

Coordination: Dr. France Woimant, Lariboisiere Hospital, Paris
Eurowilson network director: Dr Jean-Marc Trocello, Lariboisiere Hospital, Paris

The Wilson national reference centre consists of:

- 2 reference sites located in Paris and Lyon

Paris:

- Lariboisiere Hospital: adult neurology
Dr F Woimant (00 33) 1 49 95 65 27
- Paul Brousse Hospital: adult hepatology
Dr R Sobesky (0 33) 1 45 59 65 37
- Bicetre hospital: paediatric hepatology
Pr O Bernard (00 33) 1 45 21 37 90

Lyon

- HFME Children's Hospital : pediatric hepatology
Pr A Lachaux (00 33) 1 27 85 59 78
- Edouard Herriot Hospital : adult hepatology
Dr J Dumortier (00 33) 4 72 11 01 09
- Neurological Hospital: adult neurology
Pr E Broussolle (00 33) 4 72 35 76 07

- There are 6 sites of expertise in Besançon, Bordeaux, Lille, Marseille / Aix, Rennes and Toulouse.

The reference centres missions are to:

- Coordinate patient care
- Give support and care for particularly complex cases
- Propose multidisciplinary consultations (paediatricians, neurologists and hepatologists)
- Develop treatment protocols
- Inform and train professionals
- Coordinate research activities
- Provide epidemiological monitoring
- Work in direct association with patients association for Wilson's disease Bernard Pepin
- Work closely with the European group of professionals: EuroWilson

<http://cnrwilson.fr/>

The Metabolic Centre Necker Hospital, Paris

Contacts

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One of the largest paediatric centres in France including metabolic, gastro-hepatoenterology, nephrology, haematology and immunology, pneumology, and cardiology paediatric departments, as well as liver, kidney, intestinal, cardiac and blood marrow transplantation units. - Reference Centre for Metabolic Diseases.

Patient Organisation

Bernard Pepin Organisation for Wilson Disease

Contacts

Secretary
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Bernard Pepin Organisation for Wilson's disease was founded in 1989, in memory of Pr Bernard Pepin (1927-1989), famous French neurologist and Wilson's disease specialist.
Today, the organisation has 200 members...

The objectives of the organisation are :

- *Provide financial and moral support to both patients and their families
- *Encourage medical research
- *Give patients the opportunity to share information via a secured website chat room
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- *Issue association membership cards
- *Write up an Association Report with up to date information on the social welfare system, institutions and medical authorities involved in the disease
- *Organize an annual meeting where patients and professionals (National Reference Centres and Competence Centres) can share opinions, experience and access medical information directly
- *Participate in scientific symposia about the disease
- *Keep up-to-date and inform members on the latest scientific research, rules and regulations likely to impact any patient suffering from an orphan disease. The association works directly with the largest French federation involved in rare disease research

<http://www.abpmaladiewilson.fr>