



Wilson's Disease Support Group – UK  
[www.wilsons-disease.org.uk](http://www.wilsons-disease.org.uk)

## **INFORMATION ON THE WILSON'S DISEASE PATIENT REGISTER - UK**

### **What Is the Wilson's Disease Patient Register - UK and What Information will be held?**

The Wilson's Disease Patient Register - UK (*Patient Register*) held and managed by the Register Coordinator of the Wilson's Disease Support Group – UK (**WDSG-UK**) is a simple index containing a list of Wilson's disease patients within the UK who have consented to having their details included in the Register. Only the following information about patients will be kept:

- Name and address
- NHS number
- Gender
- Date of birth,
- Date of diagnosis
- Name of consultant and hospital details.

### **How will the Patient Register help Wilson's Disease Patients?**

Wilson's disease is a complex illness which affects patients in different ways and to differing degrees. **WDSG-UK** supports any initiative, particularly clinical research, which sets out to improve the lives of patients either in the short or long term. Agreeing to be on the patient register is one way in which we can potentially assist in clinical research which may lead to improvements in diagnosis and a more consistent approach to treatment in Wilson's disease.

### **How will the Patient Register work?**

Researchers will be invited to approach the Register Coordinator at **WDSG-UK** outlining the details of any proposed research and requesting to be put in touch with any suitable patients. The Coordinator will in turn write to such patients giving details of the research in question and asking if the patient would like to take part in the study. If the patient gives his/her written consent, then the details held on the Patient Register will be forwarded to the interested parties who will separately contact the patient. For each new research project, separate consent will need to be given by the patient.

### **Who will be eligible to go on the Patient Register?**

Anybody living in the UK who has been diagnosed with Wilson's disease will be eligible to have their details entered on the Patient Register. This includes patients who have received liver transplants.

### **Who will fund and manage the Patient Register?**

**WDSG-UK** will fund and manage the Register. The Register will be held centrally and maintained and kept up to date by the Register Coordinator. The Register will be operated and managed to maintain stringent confidentiality of all patient information. The Register will be managed according to the guidelines outlined in the *1998 Data Protection Act*.