

Wilson's Disease Support Group – UK

- **Supports** patients, their families and friends by providing communications for networking and a closed Facebook site for members to share their concerns and experiences.
- **Maintains** an active web site (www.wilsonsdisease.org.uk) and publishes an annual newsletter for members.
- **Reports** the latest medical information on the treatment and management of Wilson's disease.
- **Organises** an annual meeting where members and health professionals can meet and talk about Wilson's disease.
- **Raises funds** to support the Group's activities and to increase awareness about Wilson's disease.
- **Promotes** the development of a multi-disciplinary approach in the UK for the lifelong treatment and management of Wilson's disease.



Wilson's Disease Support Group – UK
www.wilsonsdisease.org.uk

Please join the Wilson's Disease Patient Register – UK and support future research into this rare disease.

We believe that the views and needs of patients with Wilson's disease should be heard and understood by health service providers. The more members we have, the greater our voice. We welcome new members.

Please visit www.wilsonsdisease.org.uk for an application form to join WDSG-UK or e-mail the Secretary of WDSG-UK, Mrs Valerie Wheeler, val@wilsonsdisease.org.uk, for further information.



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SUPPORT GROUP – UK

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WILSON'S
DISEASE
PATIENT
REGISTER
– UK

What is the Wilson's Disease Patient Register – UK?

The Wilson's Disease Patient Register – UK (the Register) is an index of Wilson's disease patients residing in the UK who have consented to have their details included on the Register. The Register is managed by WDSG-UK.

The following information is collected for each patient:

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

Wilson's Disease Support Group – UK (WDSG-UK) is the largest patient support group in the UK for adults and children with Wilson's disease. The Group is run by patients and family members who have first-hand experience of the disease.

How is this information helpful?

Wilson's disease is a complex metabolic illness which affects patients in different ways and to differing degrees. WDSG-UK supports initiatives, particularly in clinical research, to improve not only the lives of patients now but also future generations with Wilson's disease. Agreeing to be on the Register gives patients the opportunity to assist in clinical research, which could lead to improvements in the diagnosis, treatment and long-term care for Wilson's disease patients across the UK.

Who is eligible to register?

Anybody living in the UK who has been diagnosed with Wilson's disease is eligible to have his or her details entered on the Register. This includes Wilson's disease patients who have received liver transplants. Children (up to the age of eighteen) diagnosed with Wilson's disease can also join the Register, but will need the consent of a parent or guardian before their details can be entered.

How do I register?

Please visit the WDSG-UK website, www.wilsons-disease.org.uk, and download the registration form. Enter your details (or your child's), and send the completed form to the Wilson's Disease Patient Register – UK Coordinator, Mrs Valerie Wheeler.

Contact details: Mrs Valerie Wheeler,
38 Grantchester Road, Cambridge, CB3 9ED; Tel:
01223 364982; E-mail: val@wilsons-disease.org.uk
If you have any queries or do not have computer access, please contact the Register Coordinator.

Where will information on the Register be stored and who has access?

The Register was launched in 2015 and WDSG-UK currently funds and manages its administration. The Register is maintained in an electronic format at a central location and kept up to date by the Register Coordinator, who is the only person with access to the patient information on the Register. The Register is managed to ensure the strictest confidentiality of all patient information in compliance with the UK Data Protection Act 1998.

How will the data be used?

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 suitable patients. The Register 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 such a study. If the patient gives consent then details held on the Patient Register will be forwarded to the interested parties concerned who will separately contact the patient. For each new research project, separate consent will need to be given by the patient.