

Wilson's Disease Questionnaire

1) Name: _____

2) Age: _____

3) How did you hear about us?

- Self-referred / Internet search
- Neurologist: _____
- Hepatologist: _____
- Ophthalmologist: _____
- Primary care provider: _____
- Other physician: _____

4) Do you carry a diagnosis of Wilson's disease?

- Yes, newly diagnosed (within the last year)
- Yes, established diagnosis
- No, diagnosis is the reason for the visit (I / doctors think I may have it)
- No, but my family member carries the diagnosis

5) Review of Systems

Liver/GI

- Do you have any specific diagnoses related to liver or GI problems? _____
- Enlarged liver or spleen
 - Symptomatic / Asymptomatic
- Abnormal liver function tests
 - Symptomatic / Asymptomatic
- Fatty liver
 - Symptomatic / Asymptomatic
- Hepatitis
 - Chronic / Acute
- Liver failure
 - Chronic (cirrhosis) / Acute
- Do you have any of the following symptoms:
 - Nausea/vomiting
 - Jaundice (yellowing of the skin)
 - Abdominal pain or distention
 - Constipation/diarrhea

Neurologic

- Do you have any specific diagnoses related to neurologic problems? _____
- Have you ever had a scan of your brain? _____
 - If yes, was there any abnormality that you know of? _____
- Do you have any of the following symptoms:
 - Tremor
 - Involuntary movements
 - Speech problems
 - Stiffness
 - Drooling
 - Unsteady gait
 - Seizures

Psychiatric

- Do you have any specific psychiatric diagnoses? _____
- Do you have any of the following symptoms:
 - Depression, anxiety, or other mood disorder
 - Personality change
 - Irritability
 - Cognitive complaints

Other

- Do you have any known problems with:
 - Vision or abnormalities on eye exams
 - Anemia (low blood counts)
 - Skin changes
 - Kidney problems
 - Bone or joint problems
 - Heart problems

6) Do you have records of any of the following (if so, please bring with you to the appointment)?

- Liver function tests
- Complete blood count
- Basic or comprehensive chemistry panel
- Copper studies – serum ceruloplasmin, 24-h urine copper
- Eye exams
- Brain imaging
- Liver biopsy results

- Molecular/genetic studies

7) Do you need think you would benefit from seeing any of the following specialists:

- Neurologist
- Hepatologist
- Psychiatrist
- Social Worker
- Ophthalmologist
- Genetics counselor
- Physical therapist
- Occupational therapist
- Speech pathologist

8) List of current medications, including: penacillamine, zinc, trientine, etc