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