

**Online supplement: mailed questionnaire**

1. Name, first name: \_\_\_\_\_ 2. Date of birth: \_\_\_\_\_

3. Address: \_\_\_\_\_ 4. Gender:  m  f

5. Telephone number (during the day): \_\_\_\_\_

6. I suffer from Wilson disease:  yes  no (do not fill out the questionnaire)

If so, since when: \_\_\_\_\_ (year)

7. Wilson disease started particularly with the following symptoms:

neurological  psychiatric  liver  other/ none/ do not know

8. For copper removal I take the following drugs (e.g., Metalcaptase 150, Metalcaptase 300, Wilzin or other zinc preparations, trientine, etc.):

a. \_\_\_\_\_ etc.  
Name How many tablets a day?

9. I still suffer from neurological symptoms:

yes  no (do not fill out the rest of the questionnaire)

If so, please try to specify whether one or several of the provided examples apply or report your symptoms in the comment:

Postural or action tremor (e.g., a trembling of the hands if the arms are held in a stretched-out position or when moving a cup or a glass towards the mouth)

"Parkinsonism" [e.g., a trembling of the hands at rest, difficulty with fine motor control (closing buttons, smaller handwriting), slowing of movements]

"Dystonia" (e.g., involuntary contraction of muscles or involuntary movements that can interfere with speech, fine motor control or walking or can lead to an abnormal posture)

Comment: \_\_\_\_\_

10. Because of these neurological symptoms I am - or was - treated with drugs (e.g., propranolole, primidone, anticholinergics, levodopa, botulinum toxin, etc.):

yes  no (do not fill out the rest of the questionnaire)

If so, I am - or was - treated with the following drugs (please also state the beginning and the end of the therapy, if applicable):

a. \_\_\_\_\_ - \_\_\_\_\_ etc.  
Name How many tablets a day? from until

11. This treatment helped me or has helped me:

very well  well  moderately  slightly  not at all

12. May we call you in case of further questions, especially with respect to the neurological symptoms?  yes  no

13. Which physician is treating you for Wilson disease and your neurological symptoms?

\_\_\_\_\_  no one