

WILSON'S DISEASE ASSOCIATION



INTERNATIONAL

Wilson Disease Patient Lab Tracker

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WDA Medical Advisory Committee

Michael L. Schilsky M.D., Chair

WILSON DISEASE PATIENT LAB TRACKER

TREATMENT AND MONITORING OF WILSON DISEASE

The following spreadsheet is designed to help you track your most important laboratory values and tests related to your Wilson disease. Included are some tests that should be done at regular intervals, as well as some that may be done only at the start of your evaluation. Those that are done only during the initial evaluation are included separately. The tracking sheet may contain tests that your physician may feel are not required at each visit, and we recommend that you discuss this with them.

These are basic labs that will be helpful to follow your copper status and the status of liver disease but will not be able to help you follow the neurological or psychiatric symptoms if these are present. These will require continued follow-up care with your physician or specialists.

Current recommendations for the frequency of laboratory testing for many of the tests included on the Patient Care Sheet are 2-4 times annually if you are further on in the course of your disease, and more frequently if there are specific problems that your physician is addressing (see reference).

Included in the tracker are categories for common neurological and psychiatric symptoms for some affected patients. The responses to these are subjective, and you may wish to enter them as present, then **improved (I)**, **not improved (NI)**, or **worsened (W)**. Please consult your physician or specialist as to how they would like to follow these with you.

INITIAL EVALUATION

It is important to try to obtain copies of your original documents for any biopsy reports or molecular genetic studies since these will help you if you require care by other physicians. The Histology section, under Liver Biopsy, should contain discussion of any fibrosis, inflammation, or steatosis found on analysis. This "Tracker" is not meant as a substitute for your routine maintenance health care that may include such testing as immunity to Hepatitis A and B, bone density studies, ECG, fecal testing for occult blood, PAP smears and mammograms, screening and surveillance for liver cancer and other studies that your doctor would like to have you perform.

COPPER TRACKER

The copper calculators are provided as a separate spreadsheet. These will help you calculate your "free" or non-ceruloplasmin copper. Values typically should be between 5 and 15, however there is a wide range that may be seen due to the differences in technique and range for normal between laboratories, and the fact that this is a derived and not directly measured number. Therefore this value should not be interpreted in the absence of the other test results. The other calculators are for determining the results of your 24 hour urine copper. Please pay careful attention to the way that the units the results are reported to you. In Canada and the European Union, values will be in micromoles while in the US it will be reported in micrograms. The volumes are often different as well – in Canada and the EU the concentrations are often reported as per liter, while in the US it is frequently reported as per deciliter (one tenth of a liter, abbreviated dl).

Reference:

Roberts E, Schilsky ML. A Practice guideline on Wilson disease. *Hepatology* 37:1475-1492, 2003.

This reference is available at: https://www.aasld.org/eweb/docs/wilson_withcorrection.pdf

TREATMENT AND MONITORING OF WILSON DISEASE

Name: Samuel K. Wilson		Reference	Date:	Date:	Date:	Date:	Date:
Medications		Units	6/18/1998	7/13/1998			
d-Penicillamine	(mg/day)			250 tid**	** qd = once a day		
Pyridoxine (B6)	(mg/day)			50 qd**	bid = twice a day		
Trientine	(mg/day)				tid = 3 x day		
Zinc acetate	(mg/day)				qid = 4 x day		
Zinc (other)	(mg/day)						
Other medications:							
CBC/Platelets							
WBC	K/UL	4.8-10.8	6.4	7.1			
HgB	GM/DL	14.0-18.0	14.1	14.3			
HCT	%	42.0-52.0	41.2	40.9			
Platelets	K/UL	150-400	199				
Liver Function Panel							
Albumin	*Report the units and						
Total bilirubin	normal reference						
Direct bilirubin	values as your own						
Alkaline phosphatase	lab reports them.						
ALT	U/L	8.0-36	166				
AST	IU/L	13-38	67				
Alpha fetoprotein (AFP)							
Coagulation							
INR		0.0-1.1	1				
Prothrombin time	SEC.	22-33	33				
Copper and Zinc Parameters							
Serum copper							
Serum ceruloplasmin	MG/DL	20-40	23				
24 hour urine (copper/volume)	mcg/day	15-50	150	1950			
24 hour urine zinc							
Non-ceruloplasmin copper							
Urinalysis							
Protein							
WBC							
RBC							
Other							
BUN							
Creatinine							
Neurological Symptoms							
Absent	X		X				
Present	X						
Tremors	I NI W						
Speech (dysarthria)	I NI W						
Coordination	I NI W						
Swallowing	I NI W						
Insomnia	I NI W						
Other:							
Psychiatric Symptoms							
Absent	X		X				
Present	X						
Anxiety	I NI W						
Depression	I NI W						
Mood swings	I NI W						
Other:							

TREATMENT AND MONITORING OF WILSON DISEASE

Name:		Reference Range	Date:	Date:	Date:	Date:	Date:
Medications		Units					
d-Penicillamine	(mg/day)						
Pyridoxine (B6)	(mg/day)						
Trientine	(mg/day)						
Zinc	(mg/day)						
Zinc (other)	(mg/day)						
Other medications:							
CBC/Platelets							
WBC							
HgB							
HCT							
Platelets							
Liver Function Panel							
Albumin							
Total bilirubin							
Direct bilirubin							
Alkaline phosphatase							
ALT							
AST							
Alpha fetoprotein (AFP)							
Coagulation							
INR							
Prothrombin time							
Copper and Zinc Parameters							
Serum copper							
Serum ceruloplasmin							
24 hour urine (copper/volume)							
24 hour urine zinc							
Non-ceruloplasmin copper							
Urinalysis							
Protein							
WBC							
RBC							
Other							
BUN							
Creatinine							
Neurological Symptoms							
Absent	X						
Present	X						
Tremors	I NI W						
Speech (dysarthria)	I NI W						
Coordination	I NI W						
Swallowing	I NI W						
Insomnia	I NI W						
Other:							
Psychiatric Symptoms							
Absent	X						
Present	X						
Anxiety	I NI W						
Depression	I NI W						
Mood swings	I NI W						
Other:							

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Liver Function Panel							
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Direct bilirubin							
Alkaline phosphatase							
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Alpha fetoprotein (AFP)							
Coagulation							
INR							
Prothrombin time							
Copper and Zinc Parameters							
Serum copper							
Serum ceruloplasmin							
24 hour urine (copper/volume)							
24 hour urine zinc							
Non-ceruloplasmin copper							
Urinalysis							
Protein							
WBC							
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Neurological Symptoms							
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Tremors	I NI W						
Speech (dysarthria)	I NI W						
Coordination	I NI W						
Swallowing	I NI W						
Insomnia	I NI W						
Other:							
Psychiatric Symptoms							
Absent	X						
Present	X						
Anxiety	I NI W						
Depression	I NI W						
Mood swings	I NI W						
Other:							

