

# Adult Polyglucosan Body Disease Registry: Physician Form

## Instructions:

You are being asked to provide medical information on someone diagnosed with Adult Polyglucosan Body Disease (APBD), who has chosen to participate in the APBD Registry, a research project sponsored by the APBD Research Foundation and hosted by Columbia University. If you have any questions regarding the information requested on this form or the APBD Registry generally, you can contact the Principal Investigator for the study, Dr. Salvatore DiMauro, at 212-305-1662 or sd12@columbia.edu.

Please complete the following pages as thoroughly as possible, using results from the most recent physical/neurological exam performed on the patient.

If you complete this form electronically, be sure to save your entries, and return the resulting file to your patient. The patient will then upload the file to the secure APBD web site.

If you complete this form on paper, return the completed pages to your patient. The patient will then enter the data you have supplied into the secure APBD web site.

Thank you for your time, and for your contribution to the understanding of Adult Polyglucosan Body Disease.

## Clinical Manifestations

Manifestation	Present		Age at Onset	Course			
Bladder dysfunction	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Fecal incontinence	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Gait alteration	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Feet numbness	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Hand numbness	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Tremor	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Memory deficit	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Dementia	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Psychiatric disorder	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Behavioral problems	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Parkinsonism	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Autonomic symptoms (orthostatic hypotension, etc.)	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Swallowing problems	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Speech problems	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible
Other, describe:	No	Yes		Stable	Progressive	Relapsing-remitting	Reversible

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## Physical/Neurological Exam

Age at exam				
Eye Movements				
Pursuit	Normal Saccadic			
Voluntary saccades	Normal Slow			
Muscle Tone				
LL muscle tone	Normal Spastic Flaccid			
UL muscle tone	Normal Spastic Flaccid			
Strength				
LL weakness	Proximal	No	Yes	
	Distal	No	Yes	
UL weakness	Proximal	No	Yes	
	Distal	No	Yes	
Reflexes				
Snout	Normal	Increased	Decreased	Absent
Bicipital	Normal	Increased	Decreased	Absent
Tricipital	Normal	Increased	Decreased	Absent
Patellar	Normal	Increased	Decreased	Absent
Ankle	Normal	Increased	Decreased	Absent
Plantar	Normal	Increased	Decreased	Absent
Sensitivity				
Vibration	Decreased LL	No	Yes	
	Decreased UL	No	Yes	
Position	Decreased LL	No	Yes	
	Decreased UL	No	Yes	
Touch	Decreased LL	No	Yes	
	Decreased UL	No	Yes	
Pain	Decreased LL	No	Yes	
	Decreased UL	No	Yes	
Gait/Coordination				
Ataxia	No Yes			
Tandem	Normal Abnormal Unable			
Romberg	No Yes			
Dysdiadochokinesia	No Yes			
Dysmetria	No Yes			
Cognition				
Memory deficit	No Yes			
Attention deficit	No Yes			
Mini-Mental State Exam score				

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## Other Clinical Tests

CK max	Not done Done  If Done Age performed: _____ Value (IU/l): _____																																																																								
Functional bladder study	Not done Done  If Done Age performed: _____ Result:                      Normal Abnormal – Neurogenic Abnormal – Central																																																																								
Brain MRI	Not done Done  If Done Age performed: _____  <table border="0" style="width: 100%;"> <tr> <td style="width: 30%;">White matter lesions</td> <td style="width: 30%;">Periventricular</td> <td style="width: 10%;">No</td> <td style="width: 10%;">Yes</td> </tr> <tr> <td></td> <td>Subcortical</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Internal capsule</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>External capsule</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Cerebellum</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Midbrain</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Pons</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Medulla</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Symmetrical</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Asymmetrical</td> <td>No</td> <td>Yes</td> </tr> <tr> <td> </td> <td></td> <td></td> <td></td> </tr> <tr> <td>Atrophy</td> <td>Cortex</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Ventricles</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Cerebellum</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Corpus callosum</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Pons</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Cervical spine</td> <td>No</td> <td>Yes</td> </tr> <tr> <td></td> <td>Dorsal spine</td> <td>No</td> <td>Yes</td> </tr> </table>	White matter lesions	Periventricular	No	Yes		Subcortical	No	Yes		Internal capsule	No	Yes		External capsule	No	Yes		Cerebellum	No	Yes		Midbrain	No	Yes		Pons	No	Yes		Medulla	No	Yes		Symmetrical	No	Yes		Asymmetrical	No	Yes	 				Atrophy	Cortex	No	Yes		Ventricles	No	Yes		Cerebellum	No	Yes		Corpus callosum	No	Yes		Pons	No	Yes		Cervical spine	No	Yes		Dorsal spine	No	Yes
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