Adult Polyglucosan Body Disease Registry: Participant Data

Contact Information

First Name	
Middle name	
Last name	
Suffix (Jr., III, etc.)	
Mailing address	
Phone number	
Email address	
Preferred method of contact	☐ E-mail ☐ Mail ☐ Phone

Basic information

Date of birth (mm/dd/yyyy)	
Sex	☐ Male ☐ Female ☐ Other ☐ Transsexual
Race	☐ American Indian/Alaska Native ☐ Asian ☐ Black/African-American ☐ Native Hawaiian/Pacific Islander ☐ White ☐ Other
Hispanic	☐ No ☐ Yes
Ashkenazi Jewish	☐ No ☐ Yes ☐ Don't know
Mother's country of birth	
Father's country of birth	
Grandmother's country of birth (mother's side)	
Grandfather's country of birth (mother's side)	
Grandmother's country of birth (father's side)	
Grandfather's country of birth (father's side)	
Parents consanguineous	☐ No ☐ Yes
Insurance	☐ Private health insurance ☐ Medicare ☐ Medi-gap ☐ Medicaid ☐ SCHIP (Children's Health Insurance Program) ☐ Military health care (Tricare/VA, Champ-VA) ☐ Indian health service ☐ State-sponsored health plan ☐ Other government program ☐ Single service plan (e.g. dental, vision, prescription) ☐ No coverage

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Basic information, cont'd.

Highest education completed/graduated	☐ Eighth grade or less ☐ More than eighth grade, but did not graduate from high school ☐ Went to a business, trade, or vocational school instead of high school ☐ High school graduate ☐ Completed a GED ☐ Went to a business, trade, or vocational school after high school ☐ Went to college, but did not graduate ☐ Graduated from a college or university ☐ Professional training beyond a four-year college or university ☐ Never went to school

Diagnosis/History

Diagnosed with APBD	☐ No ☐ Yes
Age at symptom onset	
Age at diagnosis	
Any history of APBD in the family?	☐ No ☐ Yes ☐ Don't know If Yes: ☐ Yes ☐ Don't know Was your mother diagnosed with APBD? ☐ No ☐ Yes ☐ Don't know Any siblings diagnosed with APBD? ☐ No ☐ Yes ☐ Don't know Any other relatives diagnosed with APBD? ☐ No ☐ Yes ☐ Don't know
Diagnosed with peripheral neuropathy	☐ No ☐ Yes
Diagnosed with spinal stenosis	☐ No ☐ Yes
Diagnosed with ALS	☐ No ☐ Yes
Diagnosed with MS	☐ No ☐ Yes
Diagnosed with prostate cancer	☐ No ☐ Yes
Diagnosed with benign prostate hyperplasia (BPH)	☐ No ☐ Yes ☐ Yes