

CAP, Columbia University APBD Patient registry – enrollment update and revised questionnaire

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The APBD Research Foundation and the Mailman School of Public Health at Columbia University, along with a team of international researchers and clinicians, established the first APBD registry as of May 1, 2014. The team at Columbia, experienced in maintaining patient registries, follows Institutional Review Board (IRB) approved protocols to ensure security and privacy of registrant information. The registry collects demographic data, family history, clinical observations, and the results of physical and neurological examinations for each patient. The APBD Registry is open to both APBD patients and their family members.

Patients and their family members are encouraged to participate in the registry to aid researchers studying APBD and the effects of various treatment programs. There are a number of promising research initiatives under development, and the success of potential treatments will need to be tested over a period of time. The registry will enable the researchers to more effectively assess the results of proposed treatment programs and will facilitate human trials in the foreseeable future.

Registrants have the option to enroll anonymously with their physician serving as the point of contact.

How information is protected:

- Patient data is encrypted and stored in secured servers with 24/7 security by Columbia University
- All data and web communications are encrypted
- Access to the data is by authorized Columbia University personnel, using secured passwords
- Only de-identified data is provided to authorized parties who have been approved by the APBD Research Foundation in accordance with federal regulations
- Patients can request to enroll anonymously and/or limit the data they provide
- All direct communication with enrollees with done only through the Columbia team

As of December 2016 there are 90 people enrolled in CAP.