Job Opportunity:

Genetics Educator and Outreach Coordinator

(Part Time, Telecommute)

Summary of Duties:

- Identify carrier screening programs that do not currently test for APBD and advocate for inclusion of APBD testing in their screening panels.
- For diagnosed patients, promote enrollment in and updates to the APBD patient registry.
- Reach out to practitioner associations of neurologists, urologists, and radiologists to offer education programs and materials that may improve rate of diagnosis of APBD.
- Develop educational material for a variety of audiences. This might include gene screening organizations, genetic counselors, physicians, people of Ashkenazi Jewish heritage and other at-risk populations, etc.
- Develop and maintain effective working relationships with administrators and patient advocates in rare disease advocacy organizations.
- Serve as a resource to APBDRF leadership regarding prenatal genetic testing and genetic counseling issues.

Required Experience, Knowledge, and Skills:

1. All candidates must present a degree in human genetics, genetic counseling, or health sciences. In addition, we are seeking:
2. At least 2 years experience in genetics education/outreach or as a genetics counselor.
3. Knowledge of rare disease advocacy organizations and the issues they face in getting the word out.
4. Ability to take initiative and self-manage within a team environment
5. Excellent research, writing, and editing skills.
6. Strong speaking skills to translate complex information in a compelling and relevant way.
7. Ability to meet tight time deadlines with a calm, professional attitude.
8. Past experience in outreach into the Jewish community, a plus.
9. Proficiency with Microsoft Office Word, Excel, PowerPoint.

NOTES:
Telecommuting is allowed.

Additional Salary Information: Part time position of 10-20 hours per week. Hourly rate is negotiable, commensurate with experience.

About APBDRF
The Adult Polyglucosan Body Disease Research Foundation (APBDRF) works towards:

- Improving the rate of diagnosis of APBD,

• Guiding individuals and families affected by the disease,
• Increasing awareness of APBD among health professionals and populations affected by the disease,
• Promoting research that may lead to new treatment options and a cure.

APBD is a rare, autosomal recessive metabolic disorder that affects the nervous system. The disease typically affects adult men and women, although a newly discovered mutation may be fatal prenatally when inherited homozygously. The disease is particularly prevalent among individuals of Ashkenazi Jewish descent.

Among adults, symptoms commonly include loss of the ability to stand or walk, loss of bladder control, significantly diminished energy, problems with cognition, and a shortened lifespan. Because the symptoms are similar to those found in other, more common diseases, APBD is significantly under- and mis-diagnosed.