March 2016

Dear Rabbi\_\_\_\_\_\_\_\_(name):

As you may know, Ashkenazi Jews can be afflicted with Adult Polyglucosan Body Disease (APBD). APBD is a genetic disease that harms walking, bladder control, energy level, and other areas. See the attached primer for more details on the disease and the search for a cure.

Often misdiagnosed, APBD sufferers spend years in search for a diagnosis – if they ever find one. Fellow Jews are mistakenly told they have MS, ALS, prostate disease (men), and other ailments which have symptoms similar to APBD. Their lives become stories of medical decline, much frustration, inappropriate medications, and even useless surgeries.

***I can hardly believe it: An unprecedented opportunity has arisen for a possible cure!***

Israeli and other scientists developed a peptide to make the glycogen branching enzyme more normal, the central cause of the disease. But this peptide cannot be tested unless the APBD Research Foundation raises more funds and increases the registry of APBD patients. Even though 1 out of 68 Ashkenazi Jews carries a genetic mutation that can lead to APBD, the current registry is short of the required number of patients.

To further the peptide research and alleviate suffering, we must identify the hidden APBD cases and fill the registry. For recognizing APBD in its early stages, the APBD Research Foundation created a memory tool which is based on the initials of the disease’s name:

* A – Ashkenazi Jewish descent; Age 40-60, and
* P – Peripheral neuropathy (numbness, weakness, or tingling in the toes, fingers, hands, and/or feet), and
* B – Bathroom frequency beyond the norm, or difficulty with bladder control, and
* D – Diminished energy (This last symptom may develop a little bit later in the disease process.)

Any adult of Ashkenazi Jewish descent that sees the A-P-B-D indicators should get tested for APBD. It’s simple: A saliva sample is collected in one’s home and sent to a lab at Columbia University in New York for analysis. The analysis is being underwritten by the APBD Research Foundation. See APBDRF.org for more Information about the kit to test for the disease, the patient registry to assist scientists for a cure, and the donation process to make all of this possible.

Recently, Mount Sinai Medical Center added APBD to the 58 Jewish Ashkenazi diseases that it covers in its prenatal screening panel. This disease is very devastating for the afflicted adults as well as for their family members and friends.

The Jewish Community needs to help move this promising research forward. Perhaps you can make this plea to your congregants at Services, post it on the bulletin board, and print it in your newsletter.

Thank you, in advance, for all your help.

Sincerely

Member\_\_\_\_\_\_\_\_\_\_(name)

APBD Research Foundation