



An Open Letter to Jewish Community Members and Leaders

I have a genetic disease known as **APBD, Adult Polyglucosan Body Disease**. Could you or a loved one have it, too? Absolutely, yes. It afflicts an untold number of Ashkenazi Jews throughout the world, and it is usually misdiagnosed.

Sufferers are often told they have MS, ALS, prostate disease (men), and other ailments which have symptoms similar to APBD. Lives become medical disasters filled with useless surgeries and inappropriate medications, even as walkers and wheelchairs become an integral part of life.

Hadassah Medical Center has played a pivotal role in getting to the bottom of this devastating genetic disease. Hadassah's Dr. Alex Lossos discovered a genetic mutation in the Ashkenazi Jewish population that causes the disease. Hadassah's Dr. Or Kakhlon worked on a peptide that may lead to a cure.

Those of us correctly diagnosed with APBD have been given an unprecedented opportunity to move towards that cure. We need help from Jewish Community members and leaders. An Israeli startup company will consider paying for and running a drug initiative based on Dr. Kakhlon's peptide. For its part, the APBD Research Foundation must present a registry of 200 patients with a confirmed diagnosis.

Even though 1 out of 68 Ashkenazi Jews carries a genetic mutation that can lead to APBD, the patient registry is short. We need to identify 200 cases, otherwise we risk losing an opportunity everyone has been dreaming about.

To help the Jewish community recognize 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, man or woman,
- **P** - Peripheral neuropathy (numbness, weakness, or tingling in the toes, fingers, hands, and/or feet),
- **B** - Bathroom frequency beyond the norm, or difficulty with bladder control,
- **D** - Diminished energy (May develop later in disease process)

Any man or woman of Ashkenazi Jewish descent who is searching for a diagnosis and sees the A-P-B-D indicators in himself/herself should get tested for the disease called 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.

More information about the registry and the testing kit can be found at APBDRF.org

The Jewish community needs to be engaged quickly in order for this potential cure to move forward. Would you please share this information? It means the world to me and many others.

Thank you.

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