

Conversation Opener

I have a difficult genetic disease that's diagnosed principally among adult Ashkenazi Jews. It's known by its initials, APBD – Adult Polyglucosan Body Disease.

Currently there's no cure for my disease, but a startup company in Israel will consider paying for and running a drug initiative! I couldn't be more excited!

The offer comes with a catch: The drug company needs to see a patient registry with 200 APBD patients on it. Unfortunately, the current registry does not yet meet the threshold.

I wonder if you'd read a letter that provides more details and help in any way you can with getting the word out. It would mean so much to me and my family.