Dear T & V Community:

I am writing to you about a mitzvah that you may not know that you did, but one for which I am deeply grateful. On December 5-6, T &V hosted the 12th Annual Adult Polyglucosan Body Disease Research Foundation (APBDRF) Scientific Advisory Board Meeting.  Researchers, physicians, genetic specialists, and orphan disease experts from six different countries and dozens of institutions, met to discuss their research on the elusive Adult Polyglucosan Body Disease (APBD), an orphan disease. We learned that 1:48 Ashkenazi Jews carry one of the two common mutations, but APBD is not exclusively a Jewish disease.

There are 7,000 orphan diseases in the world. APBD is one of them. In the U.S., an orphan disease is defined as affecting less than 200,000 people. Orphan diseases affect up to 8-10% of the world population - that's 30-35 million Americans. Of those 7,000 orphan diseases, there are approximately only 400 for which there are any approved drug therapies. The pharmaceutical companies are just starting to focus on orphan diseases. But, although the need is dire, much of the initial diagnostic development and drug discovery is left to severely underfunded patient advocacy groups like the APBDRF.

When Rabbi Sebert addressed the esteemed group about allowing the synagogue to perform this mitzvah, I was overwhelmed with the sense of what it really meant to be a member of our community. I am also overwhelmed by what the APBDRF with Sharon Steinberg, our executive director, has been able to accomplish, in part with your assistance and the individual support of many T & V members.

Hadassah Medical Center, in collaboration with a U.S. site, is considering a clinical trial using a repurposed drug. And, Ionis Pharmaceutical with seed money from the APBDRF, announced the successful results of proof of concept research toward a genetic intervention therapy. In addition, Mount Sinai and another major genetics screening lab, Counsyl, will now include APBD in their screening panels. This is just a sample of the dozens of initiatives that your support is fostering.

I am deeply honored to call myself a member of the Town and Village Synagogue Community. Again, I want to express my heartfelt thanks.

Fondly,

Jeff Levenson