THE VOICE OF THE PATIENT

**Parting Words to our Researchers, Physicians, and Genetic Specialists**

First, we thank you for all you’re doing on our behalf. We absolutely need you to go down this road with us. Our Tribe is shouting: Do more! Work faster! Make us well! Help us dance at our children’s weddings. Help us give our grandchildren memories of the active and vital people we truly are.

We’re feeling so optimistic…You’re getting us to the point of a clinical trial. So, while we can’t manipulate broken genes and proteins, we’re doing what we can to help you help us. We’re marshalling forces for the trial we see on the horizon. We have:

* A patient registry at Columbia University
* A natural history study through NORD and the FDA
* Possibly, a different kind of natural history study through the FDA, Duke University, Columbia University, and Baylor Medical
* A biobank of fibroblasts

There’s more we lay members of the APBD community are doing:

* We engage in monthly telephone chats for patients and family members. Dial in and you can pose questions, talk to us directly.
* We have a website that gets 30,000-40,000 hits each month because it has been optimized to connect with people who have the hallmark symptoms of APBD
* We’re connecting with leaders of other disease advocacy groups to find populations whose treatments may also benefit from the very ideas you’re examining on our behalf.
* We’re raising money – not nearly as fast as we’d like – so we can provide seed money that will let you test your ideas.

With all wishes for success,

Harriet Saxe

APBDRF Board Member