Hello to all:

Let me take a moment to reintroduce myself.  Our family has been living with APBD for decades.   
My husband (Chuck) has it, along with several other members of his family.  Chuck and I attended the last 3 APBD research conferences in NYC, and we felt instantly drawn to other attendees who also live with the disease.  One thing lead to another, and the APBD Research Foundation leadership asked if I'd volunteer to help launch a chat room.  Of course I would!  The first telephone call happened this past January.

Kudos to everyone who's contributing to our group bonding and our efforts to share our layman's view of APBD.  If you haven't yet joined the conversation, please consider yourself invited to our next chat session.

**Mark your calendar for Wednesday, April 23 at the following time:**

11:00 a.m. Pacific Time

12: noon Mountain Time

1:00 p.m. Central Time

2:00 p.m. Eastern Time

8:00 p.m. in Western Europe

**On the 23rd, dial**[**(712) 432-0800**](tel:%28712%29%20432-0800)**.  Then enter access code 865672#**

**As a group, we're in a formative stage. Here's what I noticed during our March 19 chat:**

* We get new participants on the line who need to introduce themselves as well as meet our other contributors.
* Some of our members arrange their day/week in order to glean info on an announced topic. They feel disappointed if we don't cover that topic.
* Every question posed by a member has an urgency to it.

This brings me to a couple of thoughts and a few questions for you:

**First Item -- It takes time to go through introductions at the start of the call.  To use our time to best advantage, it might be nice to create a "Who's Who" document.   I imagine the list containing a mini-introduction for each person who chooses to be included.**

* For APBD patients: Your mini-intro would contain first name to be used during a call, city/state where residing, age as of January 2014, age when your symptoms sent you on a search for a diagnosis, and age when you got your APBD diagnosis.  No phone numbers.  No email addresses.  No last names.
* For others who call in: Your mini-intro would contain first name to be used during a call, city/state where residing, and your connection to APBD.  No phone numbers.  No email addresses.  No last names.

We recognize your right to privacy. Identifying yourself in any way is entirely your choice.  However, if a chat room participant doesn't provide a mini-introduction for the "Who's Who" list, I suggest that we do not send our list to that person.**Please let me know how you feel about a "Who's Who" list and if you'd be willing to provide a mini-introduction for yourself.**

**Second Item -- The bulk of the time during our call ought to be available to you to address your APBD-related questions, concerns, and discoveries.  I would, though, like to reserve a small amount of time each month for one pre-advertised topic.  Do I have your concurrence to shape our chat time that way?**

Looking forward to your answers,

Harriet Saxe

Portland, Oregon, USA

**Legal Stuff:**  "This chat room exists as a source of general information only.  The contents discussed do not represent therapeutic recommendations or prescriptions.  Users of the chat room are advised to consult their personal physicians for specific information or advice."