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Patient Corner

In this section you will find personal accounts of people affected by APBD. The APBDRF as a patient support group **does not** endorse any health practitioners, therapies, medicines, etc.

[Click here](#) to see our *Searching for a Diagnosis* Brochure

[Click here](#) to see our new trifold brochure for patients and clinicians

Thanks to the work of David Epstein, our organization has been

Letter from the President

Dear fellow members of the APBD community,

I am proud and excited to tell you of a major step in our fight to find a cure for Adult Polyglucosan Disease - an important Jewish genetic disease. Today I announce the opening of the APBD Patient Registry. The registry is safe, secure, and essential to finding treatments. As potential treatments are discovered, clinical trials will be performed to validate their safety and effectiveness. These trials will need diagnosed APBD patients to try out new approaches to treatment. A patient registry is an ideal method for identifying these individuals.

Since it is likely that most people now affected by APBD have no idea that this is the cause of their illness, we are also beginning an awareness campaign to get the word out [See our new Searching for a Diagnosis brochure.](#)

Please go to the APBD Research Foundation website at www.apbdrf.org for information on joining the registry.

All the best,
Gregory Weiss
Founder and President of the APBDRF



Registry Announcement

The APBD Patient Registry now open: [Join the APBD patient Registry](#)

The APBD Research Foundation and the Mailman School of Public Health at Columbia University, along with a team of international researchers and clinicians, is establishing and maintaining the first APBD registry as of May, 1, 2014. The team at Columbia is experienced in maintaining patient registries and follows Institutional Review Board (IRB) approved protocols to ensure security and privacy of registrant information. We will be collecting demographic data, family history, clinical observations, and the results of physical and neurological examinations for the registry. **The APBD Registry is open to both APBD patients and their family members.**

Patients and their caregivers are encouraged to participate in the registry to aid the researchers studying the disease and the effects of various treatment programs. There are a number of promising research initiatives underway and the success of potential treatments will need to be tested over a period of time. The registry will enable the researchers to more effectively assess the results of upcoming treatment programs and will facilitate human trials in the foreseeable future.

Registrants have the option to enroll anonymously with your physician serving as your point of contact.

included in the Resource Central Section of [Neurology Now](#) magazine. You can read it online here, and order a FREE subscription to the magazine as well.

[Better Branches: Alma Hecht's personal blog about living with APBD](#)

[The Story of an APBD Patient by Phillip Adiv](#)

Allied Organizations

[Association for Glycogen Storage Disease](#)

[Association for Neuro-Metabolic Disorders \(ANMD\)](#)

[The Dana Foundation](#)

[The Doctor's Doctor](#)

[Genetic Alliance](#)

[Jewish Genetic Disease Consortium \(JGDC\)](#)

[Muscular Dystrophy Association](#)

[National Organization for Rare Disorders](#)

[National Tay-Sachs & Allied Diseases Association \(NTSAD\)](#)

Instructions to Enroll in the APBD Registry

To enroll in the APBD Registry

1. [Go to the APBD Registry web site](#)
2. Click on the red "Join the APBD Patient Registry" button
3. Read the document titled "Understanding Your Participation"
4. Complete the online Consent for Participation form, including providing a user ID, password and email address
5. Click the "I Consent" button.

Now you have joined the APBD Registry

1. If you'd like researchers to contact you, enter your contact information, then click Next
2. Enter some basic information about yourself, then click Next
3. Enter information about how APBD has affected yourself and your family, then click Next
4. Download a Physician Form and give it to your doctor to fill out (See additional instructions for options on filing out the Physician form.)
5. Upload the Physician Form to the APBD Registry web site, or click the "View Data" button and enter the information yourself

Remember, you don't have to provide any information you don't want to provide. You can join the Registry anonymously by simply skipping the contact information page. Please use the comment/question fields located on the bottom of most sections for any clarification you think is necessary.

APBD Patient/Family Registry Completing the Physician Form

Completing the form on paper

1. [Log in to the APBD web site](#)
2. Click on the "Exam(s)" tab at the top of the page.
3. Click the "Download Physician Form" link.
4. Save the APBD Physician Form (APBD_Phys_Form.pdf) to your computer.
5. Open the physician form in Adobe Reader or Adobe Acrobat.
6. Click the Printer icon to print the form.
7. Give the printed form to your doctor to complete.

Completing the form electronically

1. [Log in to the APBD web site](#)
2. Click on the "Exam(s)" tab at the top of the page.
3. Click the "Download Physician Form" link.
4. Save the APBD Physician Form (APBD_Phys_Form.pdf) to your computer.
5. Either email the file to your doctor, or copy the file to a portable USB drive (thumb drive) and give the thumb drive to your doctor.
6. Ask your doctor to open the physician form in Adobe Reader or Adobe Acrobat.
7. Have your doctor complete the form on their computer.
8. When they attempt to close the file, the software will prompt them to save their changes.
9. Ask your doctor to return the completed form to you, either by email or thumb drive.

Entering the information into the registry automatically

1. [Log in to the APBD web site](#)
2. Click on the "Exam(s)" tab at the top of the page.
3. Click the Upload File button. When prompted, select the completed physician form and click "Open".
4. Click "Next" on the right side of the page to finish entering data into the registry.

Entering the information into the registry by hand

1. [Log in to the APBD web site](#)
2. Click on the "Exam(s)" tab at the top of the page.
3. Click the View Data button.
4. Enter the data from the physician form into the web site.
5. Click "Next" on the right side of the page to finish entering data into the registry.

[Join the APBD patient Registry](#)

Videos

David - A patient discusses the importance of the Adult Polyglucosan Body Disease Registry.



In this video David talks about the value of the Adult Polyglucosan Body Disease Registry. After researching it, he learned that the importance of people participating in the registry is that when treatment trials are ready to begin, there will be a ready population of APBD patients that can participate in those trials.

Richard Buchsbaum - is the Senior Data Manager at the Statistical Analysis Center/ Biostatistics Department Mailman School of Public Health Columbia University



Richard Buchsbaum: Establishing APBD Registry

In this video he talks about what an APBD patient registry is.

Watch Richard Buchsbaum: Establishing

APBD Registry



Richard Buchsbaum: Significance of APBD Registry

In this video he talks about the significance and value of an APBD patient registry.

Watch Richard Buchsbaum: Significance of APBD Registry



Richard Buchsbaum: Full Length

In this video he talks about what an APBD patient registry is and the significance and value of an APBD patient registry.

Watch Richard Buchsbaum: Full Length

DR Kolodny -

Edwin H Kolodny, M.D.

APBDRF scientific advisory board,

Professor Emeritus; Research Professor; Dir Neurogenetics

Department of Neurology (Neurology)

NYU Neurology Associates



APBDRF Next Steps: Patient Registry

Please watch Dr Kolodny's short video about the importance of a patient registry.

Watch *APBDRF Next Steps: Patient Registry*

www.apbdrf.org

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