

# & WOMEN

“ For years, I suffered urination problems in silence, but after talking with APBD colleagues this is as common as stumbling and falling—although far more humiliating, angering, and disheartening. Yet I find joy and face the challenge crafting as gracious and enjoyable a life as possible. Here I am in Hawaii with my handy trekking poles. I got around well and even swam in the calm ocean three times a day. ”



HELP FIGHT

## APBD & ALLIED DISEASES

DONATE

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**APBDRF**  
ADULT POLYGLUCOSAN BODY DISEASE RESEARCH FOUNDATION

A registered 501(c)3 non-profit organization  
Contributions are tax deductible to the extent permitted by law

# DO YOU HAVE...

- Worsening leg stiffness?
- Foot or leg numbness?
- Urination problems?
- Are you searching for a diagnosis?

**SO WAS YOSSI.**

*Now he has the diagnosis and he is joining with others who are working to find a cure.*



## ADULT PB DISEASE (APBD)

Contact us and let us help you get a diagnosis today!  
Visit [apbdrf.org](http://apbdrf.org) for more info.

YOSSI IS NOT ALONE.  
ADULT PB DISEASE AFFECTS

# MEN...



“ It took 13 years for a proper diagnosis. In my early 50’s, I first experienced numbness in my hands, cramps, stiffness and heaviness in my legs. Also muscle twitching, soreness, foot drag and stumbling. Initially, I was incorrectly diagnosed with hereditary peripheral neuropathy. I participated in a research trial conducted by the National Institutes of Health. Finally, the Kennedy Krieger Institute in Baltimore, Maryland came up with the correct diagnosis. ”

## ADULT PB DISEASE (APBD) ADULT POLYGLUCOSAN BODY DISEASE

### What?

A genetic disease

### Where?

Affects the nervous system: legs, bladder, brain, spinal cord

### When?

Onset as early as age 35

### Why?

Low activity of glycogen branching enzyme (gene GBE1)

### How common?

One study shows a 1:34.5 carrier frequency rate in Ashkenazi Jews

### Is APBD exclusively a Jewish disease?

No

### OFTEN CONFUSED WITH OTHER ILLNESSES SUCH AS:

MS, ALS, Alzheimer's, Peripheral Neuropathy, Prostate Cancer, Benign Prostatic Hyperplasia (BPH), Symmetric White Matter Disease, Spinal Stenosis



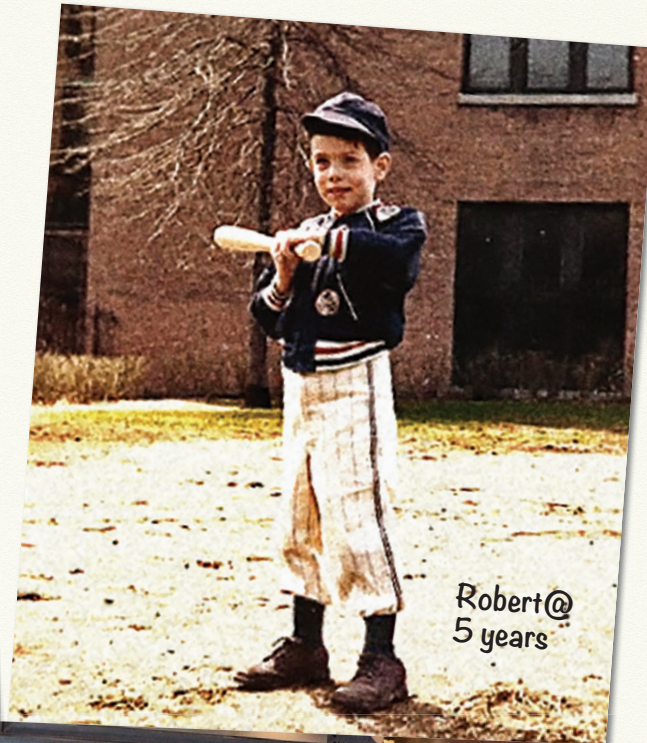
A SIMPLE BLOOD  
TEST CONFIRMS  
THE DIAGNOSIS

## MEET ROBERT A TOP HOLLYWOOD PHOTOGRAPHER

“ In my late forties I began experiencing ataxia, drop foot, falling, edema, urinary incontinence and an active right hand tremor that made eating and serving food difficult or impossible. After seven years of every kind of test imaginable, I finally received the correct diagnosis at UCLA and became part of the APBD community. ”



Robert 2008



Robert@  
5 years



Robert now

## WHAT ARE WE DOING TO FIGHT APBD?

### RESEARCH AND THE REGISTRY

Our international team of researchers is moving us towards **clinical trials** that will identify treatments for and prevent the damaging effects of APBD. To facilitate these human trials, the APBD Research Foundation (APBDRF) in collaboration with Columbia University established the first APBD registry of people with APBD. The registry is privacy-protected by Institutional Review Board (IRB) protocols. There is also an option to enroll anonymously with your physician as your contact.

JOIN  
THE APBD  
PATIENT REGISTRY



VISIT  
APBDRF.ORG  
TODAY!



DO YOU SEE  
YOURSELF OR  
SOMEONE YOU  
KNOW IN OUR  
STORIES?

- > GET TESTED
- > JOIN THE REGISTRY