Hi All:

The technical name, Adult Polyglucosan Body Disease, masks the reality of the experiences of the people dealing with APBD. Yet those personal experiences are among the most pressing concerns to patients, family members and others who want to know about the disease, as evidenced by the fact that the personal narrative section is one of the most visited pages on our website, APBDRF.org. There, visitors are privy to the compelling stories of individual patients and their loved ones. We want to expand on this section of our website and draw more people to it. Toward that end, we are very pleased that we have Robert Zuckerman, a prominent photographer and APBD patient, to help us.

Through books and websites of photos and stories, Robert Zuckerman has dedicated his life to recording personal narratives. The nature of Robert’s work is exemplified in his piece ‘KindSight with Judith Kraier’ and an article from the Forward written about him, attached below. Robert will now bring his vast experience to an exploration of the experiences of APBD patients, and his interviews and photographs will be a highlight of our website.

We hope by this initiative to raise awareness and further educate the public about APBD. The possibility that there may be thousands of patients as yet undiagnosed cannot be ignored. We also want emphasize that the work our researchers are doing will benefit allied diseases as well.

If you are interested in supporting or getting involved in this initiative, please contact me.

Thank you!

Gregory Weiss

Robert Zuckerman and Judith Kraier
Dallas, Texas  March 1, 2011

In late 2010, after over seven years of extensive testing, I am diagnosed, at UCLA, with a rare genetic condition called Adult Polyglucosan Body Disease. At the time, there are...
While researchers chip away at finding the cause and cure for APBD, patients, partners, and caregivers seek work-arounds for disease symptoms. "Tribe" members are constantly on the lookout for tips and ideas to help blunt their challenges. "Tribe" members are constantly on the lookout for tips and ideas to help blunt their challenges. Visit apbdtube.com, to see what we have to share.

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 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 Adi

Robert will be in NYC next for the opening of his 92Y exhibit, which is September 4th.

When we showed Robert this Newsletter and spoke to him about our upcoming APBDRF National Outreach Initiative he said "Love the newsletter and am honored and excited for the opportunity to create KINDSIGHT® pieces about my comrades in the APBD community"

Please save the date: SEPTEMBER 4TH 2014

Robert Zuckerman, photographer/author/speaker/mentor, now paraplegic from APBD, is scheduled for a solo exhibition of his coveted KINDSIGHT® series at the 92nd Street Y in Manhattan opening on September 4th running through October 23, 2014.
This exhibition is presented in association with The Adult Polyglucosan Body Disease Research Foundation (www.apbdrf.org). APBD is a late onset genetic disease which is untreatable and progressive and affects primarily Ashkenazi Jews. Robert has this disease and at its current stage, he is paraplegic. His hope is to help bring awareness about APBD to the communities of the 92nd Street Y, New York and the world, one way being a series of KINDSIGHT® pieces about the growing population of those afflicted with APBD.

Portions of proceeds from sales of prints and books will go to the APBDRF and to Robert’s ‘The Real Open Carry’ initiative, in which cameras and ongoing photography mentoring will be introduced to at-risk populations to foster alternative life pathways to violence and crime.

For further information, please contact: robert@robertzuckerman.com or 323.864.3100

SEE THE FULL PRESS RELEASE HERE

And then join us on Sunday, September 7th for our private reception. See Invitation HERE

ARTICLE ORIGINALLY APPEARED IN:

The Arty Semite

The Benefits of 'Kindsight'
For his first gig as photographer in Hollywood in 1990, Robert Zuckerman took pictures on the set of "Sunset Beat," the pilot of a short-lived TV-series. It featured policemen who went undercover as bikers and Zuckerman still remembers one of the long-haired, leather-clad actors, who was barely known at that time. His name was George Clooney.

Since then Zuckerman, who produced commercials before becoming an independent photographer, has taken pictures at countless movie sets – from "I Know What You Did Last Summer" and "The Blair Witch Project" to the "Transformers" movies and "Terminator 3." He has also made portraits of numerous celebrities, including Leonard Cohen, Goldie Hawn and Will Smith.

In 2002, Zuckerman discovered another passion: Documenting small encounters in everyday life. He started the Kindsight Foundation, and posted photos and stories on his blog, which is also featured on The Huffington Post. In 2005, a photo book titled "Kindsight" was published.

Zuckerman, who now lives in Miami, gives speeches about his project and holds workshops for students, in which he challenges them to come up with their own Kindsight pieces and question the violent content of Hollywood movies.

He spoke to the Forward’s Anna Goldenberg about his work with Holocaust survivors, his favorite Jewish celebrity and why he occasionally puts on tefillin.

CLICK HERE TO READ THE FULL INTERVIEW

Read more: http://blogs.forward.com/the-arty-semitic/192725/the-benefits-of-kindsight/#ixzz33fwCE7fM

Robert gives back to his community:

Robert Zuckerman's Portraits exhibit, featuring additional works from his Time Machine series, hosted by Moreno's Cuba at The Riviera Hotel in Miami Beach, on Friday, June 6, 2014, and presented in association with Miami Dade School Superintendent (also National Superintendent of the Year) Alberto Carvalho was a great success.

Robert's portraits of legendary actors, artists and world figures are at once intimate, iconic and thus, memorable. His Time Machine imagery, consisting of originals dating back to the mid-1970s, then vaulted untouched for over three decades, then un-vaulted and printed, created a powerful reconnection with his earlier life, thus the name Time Machine.

Fifty percent of Robert's proceeds went to the start-up of Robert's Open Carry™ program, in which cameras and ongoing photography mentoring are introduced to at-risk youth to foster and nurture alternative life pathways to guns and violence (see below).

www.robertzuckerman.com
www.huffingtonpost.com/robert-g-zuckerman
top IMDB world photographer ranking multiple times in recent months, even though paraplegic
Pictured: Front: Robert G. Zuckerman, Rear, L-R: Major Arnie D. Weatherington, Captain Ivan E. Sylva, Ms. Maya Holton, all of Miami-Dade Schools Police Department. Initial meeting May 15, 2014 to discuss implementation of Zuckerman’s "OPEN CARRY" program - not the open carry of guns but of CAMERAS - in which cameras and ongoing photography mentoring, and their inherent potential for goodness and life-richness, are brought and given to at-risk-youth to provide an alternative life pathway to guns, crime and violence. Stay tuned!
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