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APBD in the Media:

APBD article and advertisement in the *Jewish Georgian*, a Jewish paper in Atlanta.

P.13:Adult polyglucosan body disease: what people of Ashkenazi Jewish descent need to know.

DOWNLOAD

[Article - pg. 13](#)

[Ad - pg. 32](#)

APBD article in FORWARD's August 15th Special Genetic Edition

See page 19 "Genetic Nerve Disease Puts Photographer on Other Side of Lens"

[DOWNLOAD ARTICLE](#)

From the

Letter from the President

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

Webmaster:

[CLICK HERE TO SEE OUR NEW APBD LANDING PAGE](#)

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.

While researchers chip away at finding the cause and cure for APBD, patients, partners, and care givers seek work-arounds for disease symptoms. "Tribe" members are constantly on the lookout for tips and ideas to help blunt their challenges. Visit apbdtribe.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 Adiv](#)

Article of Interest:

[The Search for a Diagnosis](#)
Having a rare disorder is difficult. But having a rare disorder and not knowing what it is or how to treat it is even worse. Find out how long it takes between

around fifty known cases in the world, affecting all or mostly Ashkenazi Jews (meaning Jews of Eastern European heritage). The projected course of the disease, I'm told, is paraplegia, bladder and prostate impairment, tremors of the upper extremities and dementia, with no set time frame. Having been admittedly loco for most of my life, I'm not worried about dementia and, having been a primary caregiver for my quadriplegic half sister Patti for over two decades gives me perspective on the physical impairment I'm experiencing now and what awaits. I enroll in the one existing clinical trial for APBD (as it's abbreviated) at Baylor Medical School in Dallas, run by the venerable Dr. Raphael Schiffman and his esteemed colleague, Mary Wallace. The clinical trial involves quarterly visits to Dallas, each lasting a few days, consisting of a battery of tests which are comparatively measured on subsequent visits. On my first day of testing, Mary asks me if I want to meet another afflicted person who has been in the clinical trial for a year and is just finishing her current visit at Baylor. Mary tells me her name, Judith Kraier, and that she is an Israeli woman now living in South America. That afternoon, while in Mary's office, Judith walks in. As Judith enters the room, our eyes meet and there is instant, complete connection, as if we are family and we have known each other our whole lives. I've experienced similar things with others, but never to this full, unimpeded degree as now with Judith, Words are unnecessary and inadequate as oceans merge. We go outside and, with Mary's help, make this photograph, then Judith gets in the van to the airport and home. After this, we stay in touch by email, especially on Fridays as we wish each other Shabbat Shalom (a good Sabbath). She invites me to visit her, but I am not inclined to leisure travel, due to various factors, including limited finances from a reduction of work being offered to me resulting, it appears, from the perception in the biz that my condition has hampered my ability when, in fact, just the opposite is true. At one point, Judith tells me it has become increasingly difficult to walk, which I can relate to. Then, our communication falls off. I figure we are both going through challenges in life and our silence is symptomatic of this. But she is always in my heart and thoughts and a Friday doesn't pass that I do not think of her. At one point I write to her with apologies for my unsociability, but do not hear back. Then, a few month ago, I get a call from Mary telling me that Judith's daughter has informed her that Judith has inoperable brain cancer. This explains things as I process the implication of the unspoken. I ask Mary for Judith's daughter's contact information but do not press the matter when there is no response. I understand. And then, after a little time has gone by, I call Mary for an update and she tells me that Judith has passed away. I run the cycle of regrets, what ifs and wish-I-hads, but mainly give thanks that Judith is now out of suffering, and vow to make the best home I can for her in my heart, my thoughts in how I live on, honoring the warm, kind, gentle yet strong spirit of my sister of many lifetimes, until we meet again.

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 KINGSIGHT® pieces about my comrades in the APBD community "

Please save the date: SEPTEMBER 4TH 2014

Robert Zuckerman, photographer/author/speaker/mentor, now paraplegic from APDB, is scheduled for a solo exhibition of his coveted KINGSIGHT® series at the 92nd Street Y in Manhattan opening on September 4th running through October 23, 2014.

symptoms and diagnosis.

Allied Organizations

[Association for Glycogen Storage Disease](#)

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

[The Dana Foundation](#)

[The Doctor's Doctor](#)

[Genetic Alliance](#)

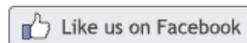
[Jewish Genetic Disease Consortium \(JGDC\)](#)

[Muscular Dystrophy Association](#)

[National Organization for Rare Disorders](#)

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

**VIEW OUR
NEW APBD
LANDING
PAGE**



Robert G. Zuckerman is a 40-year-old man who has been paraplegic since the age of 11. He is a member of the 92nd Street Y and has been a member since 2002. He is a member of the 92nd Street Y and has been a member since 2002. He is a member of the 92nd Street Y and has been a member since 2002.



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92nd STREET Y
140th STREET

The **92nd Street Y** in New York City proudly presents

KINDSIGHT®

by

ROBERT G. ZUCKERMAN

Begun in 2002 in the wake of 9-11, KINDSIGHT® uses photographs and accompanying texts to illuminate and celebrate the richness of everyday life through random encounters and moments. With KINDSIGHT®, any moment or encounter can be a story of life's richness. Through the years, countless people around the globe have testified how KINDSIGHT® has changed their viewpoint and conduct for the better.

Please join us for the OPENING RECEPTION
graciously hosted by

JEFF L. ROSENHEIM

Curator in Charge, Department of Photographs
THE METROPOLITAN MUSEUM OF ART

When: Thursday, September 4, 2014 from 5 to 7pm

Where: 1395 Lexington Avenue (at 92nd Street)
New York, NY 10128

More info: 212.415.5528, 212.415.5500, rgilson@92y.org

Thank you.

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'

By Anna Goldenberg



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-semite/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

OPEN CARRY MEETING

Miami FL
May 15, 2014



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!

Jojo runs for **APBD**

Every step every breath brings us closer to a cure



26.2 Miles

\$26,200

SUPPORT HER RUN IN
The 2014 NYC Marathon
November 4, 2014

Our goal is to raise \$26,200
to continue the critical treatment research
being conducted by Dr. Orhan Akman
at Columbia University.



[Click Here to Donate](#)

www.apbdrf.org

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