Writing about Alzheimer’s

It’s as easy as one, two, three (years) if your father kept his father’s brain in a jar.

This is the story of the book.
How to preserve the contents of my father’s head?
The trajectory of an idea.

Beau’s MRI: Atrophy consistent with A.D.
What to do with our family history?

Stewing about the P.I. while in Singapore.

Manila 1938

Clark Air Base 1965

Beau
Nature vs. Nurture

Bercaws vs. Alzheimer’s
Down Memory Lane

In an art exhibit on Alzheimer's, a writer finds shades of her own past

BY NANCY STEARNS BERCOW [06.23.10]

TAGS: aging, essay, health, health & fitness, health care, mental health
When All Isn’t Enough to Foil Alzheimer’s

By NANCY STEARNS BERCAW
Published: January 17, 2011

My father knew it was coming. Alzheimer’s disease had been on his radar ever since his own father died of it. Witnessing the catastrophic deterioration of a man who had been sharp enough to work for Gen. Douglas MacArthur, my frightened father was inspired to become a neurologist. Perhaps the pursuit of medicine could stave off what he believed was a genetic inevitability.

As an ever-present reminder of that threat, he kept an atrophied brain in a jar on his desk. That brain, I recently discovered, belonged to his father.
Stage One

Long before people develop symptoms of Alzheimer’s, the disease is beginning its invisible assault.

Stage Two

People hurtling toward an Alzheimer’s diagnosis sometimes show mild cognitive impairment. They still function normally to the outside world, but family and friends might notice very slight changes.

Stage Three

An Alzheimer’s diagnosis is made when the patient’s memory, thinking and behavioral symptoms show marked decline, thereby rendering them unable to function in the world.

Bringing all the pieces together.

WRITING THE BOOK

2010-2012

“We are linked by blood, and blood is memory without language.”

—Joyce Carol Oates
“We taunted the python with a live chicken. I danced that chicken in front of the snake’s eyes like the snake charmers I had seen in India. I pretended the chicken was the pendulum of a clock and I tried to hypnotize the python with it. The snake’s muscles relaxed and someone grabbed the boy.”

“Weren’t you scared?”

“Bercaws and Filipinos aren’t cowards.”

“Are Filipinos scared of Bercaws?” I am afraid of my father—not certain which one that made me. I wonder if Beau’s father—whom he called Berc—had the same effect on my dad. Berc lives in the Veterans’ Hospital in Roanoke because he forgot everything, including his family and himself.

“Everyone’s afraid of Bercaws,” my dad says from the driver’s seat, laughing uproariously. I can see his big blue eyes squinting and watering in the rear-view mirror.
When I feel better, I walk down Asin Road, where the famed Baguio furniture makers congregate to sell their wares. This is where my father had an enormous desk constructed out of the indigenous kamagong wood. The desk was made to my father’s specifications. It accommodated his great height and held his piles of journals, files, paperwork, reflex hammers and prescription pads.

And his father’s brain in a jar at the center of it all.
“I’d sure appreciate it if you’d take me home,” he says flatly, and then turns away.

I stare at the wind chime and swallow hard. He didn’t actually ask me to take him home, which he knows I can’t do. He made a statement that requires no action, but yet made his feelings known.

I fantasize about taking him home: maybe to the farm in Virginia. I could try to buy it back from the Barbers. He’d know exactly where he was there.

Or to Clark Air Base in the Philippines. We could get an apartment and go see the South Seas. He could die where he saved people from dying, instead of dying with patients. Alzheimer’s taunting him to the bitter end.
BIAJ Blog, Spring 2011

A MEMOIR OF MEMORY

Dear Rememberers,

We were both there. But you remember this thing; I remember the other thing. Is one of us wrong and the other right? Not necessarily. I think we’re both entitled to our memory of events. Our own perspective based on where we were in the world of our heads at the time.

I raise this issue because Brain in a Jar is ready to launch, and when it does, my memories of my father will come to bear. Each story in the book represents a moment in time with Beau. My time.
Populating the blog with stories from the book. Generating a following while agent tries to sell manuscript.
Dear Bob,

Newt just let me know that he thinks the intro is fantastic and he’s pleased to be associated with it. He also thanked you, Nancy, for your kind note.

I made a few (what I believe are) very minor tweaks to a couple sentences to be in line with what Newt is saying about Alz in his other communications on the trail. Bob, if you prefer the way you had it, my sense is that Newt would be fine with your original version.

Nancy, my thanks to you for what I’m sure will be an important contribution to raising awareness and stirring this country to action.

Robert Egge
Vice President for Public Policy and Advocacy for the Alzheimer’s Association
Brain in a Jar is an American-gothic tale of love, grief, genetics, obsession, adventure, fear and courage. The Bercaws might break your heart, but they’ll also remind you why Alzheimer’s disease must take center stage in politics, medicine and art.

Bob Kerrey and Newt Gingrich

June 2012

New York Times article on families in Colombia.

Literary Agents, Jay and Priya, from Singapore.

The Diaper Project

Eric M. Reiman, MD
Executive Director, Banner Alzheimer's Institute
Co-Director, Alzheimer's Prevention Initiative

Approached by UF for Fund

Beau gets sicker.
March 15, 2012

Simon and Schuster says no.

“This memoir’s extraordinarily well-written and felt. She’s a real writer. That said, a colleague of mine at the Free Press (a sister imprint to S&S, as you know) has just signed up a book with an overly similar set-up.”

April 2, 2012

Dr. Beauregard Lee Bercaw dies.

Fellowship created in his name at the Brain Institute, UF Medical School.

Summer 2012

What’s next?

Will Brain in a Jar get published?

Will the Fellowship be funded?

Will I get AD like my DAD and grandfather?

Sounds like another book.

Mermaid in a Bottle?

What Beau and Alzheimer’s Have Taught Me
by Nancy Stearns Bercaw

My father was born to be a neurologist. His courage infected me, just as it did his patients. You were in safe hands with Dr. Bercaw. You felt protected even if you were facing a very frightening diagnosis.

The only thing my father feared was that he was born to get Alzheimer’s disease. After watching his own father die in 1971 from what was then a little-known malady, Beau wondered if he’d inherited the gene.

As my father got older, he began experimenting on himself. He took upwards of 72 supplements a day in the hope of staving off Alzheimer’s disease — or maybe even finding a cure. He also shifted his attention to me, who he saw as his genetic twin. For my 35th birthday, Beau sent me the ApoE test. He called me with the results.

“You have what I have. And I have what my father had,” he said as if he’d shot his own daughter on purpose. He hung up the phone crying.

My brilliant father is now in memory care in Naples, Fla. He doesn’t remember very much these days, but I can still see the doctor in him. He watches the other residents the same way he used to look at his patients: with love and compassion, and the irrepressible desire to save their lives.

We need more Beau Bercaws in this world. The loss of mine leaves a gaping hole in neurology as well as in my heart. The Dr. Beauregard Lee Bercaw Fellowship will preserve my father’s memory while funding someone willing to take up his battle with Alzheimer’s. By donating, you help train the next generation of fearless indefatigable neurologists. The kind you’d want by your side if the battle against AD becomes your own. Beau’s wife, Nora, and I invite you to help ensure that Dr. Bercaw is more than a memory.

Bercaw Fellowship

The Bercaw Fellowship will allow promising young neurologists to be trained in Alzheimer’s and other dementia related conditions. No fate can be more terrible for a person and their family than to lose their ability to remember, recognize, feel, and communicate. The best means of defeating these diseases is making sure we have physicians and researchers going into this field with all the necessary expertise and training required.

The End. Or is it?
No *Grey* Matter What

*Brain in a Jar* is a lasting account of my life with Beau Bercaw and Alzheimer’s Disease.

Nothing can take that away.