Newsletter of the Brain Research Foundation Vol. 9, No. 1, 2008





My Son's Name Was Fred (paperback, 417 pages) is available from the BRF for \$25 per book (includes shipping).

To place an order, please call BRF at (312)759-5150.

When I read Gwill's book about her son Fred's disease, I was struck by the depth of what she revealed about herself. When you suffer as much as she did, to find help, you reveal your soul. Gwill did. It is a book that every family victimized by this disease must read.

> -William E. Fay, Jr. Brain Research Foundation

# My Son's Name Was Fred

Read what Gwill Newman has to say about a book that took her 25 years to write. My Son's Name Was Fred tells the story about her son's ill-fated life and death.



In my book I relate the facts behind my letter to the *Chicago Sun-Times* (see page 2). The book is not a gentle memoir. It is the truth. I explore, to the best of my ability,

the genetics, family, home, environments, education, travel, adventures, traumas, including a devastating and mysterious fire, that all might have played a role in the development of my son's illness.

I also write about the manifestations of Fred's schizophrenia. About some of the doctors and hospitals and, perhaps in too much detail, I describe the mental institutions and Fred's death.

The book also tells the love story about a man who was willing to become the surrogate father

#### **In This Issue** Dear Friends

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of my severely mentally ill son. A man I was eventually able to marry and who—because of his position as a foundation executive and a former civil rights lawyer who headed a project concerning the Administration of Justice—was able to cause all kinds of positive programs for the mentally ill to occur, from housing to advocacy to research programs that are still being replicated.

My book also speaks about women, particularly mothers, and the finally discredited psychiatric teaching that there was a person termed a schizophrenagenic mother who—it was said—actually caused schizophrenia.

And finally it is about all the positive things that can happen from brain research, knowledge that can affect everything from the practice of medicine to how we educate our children, how we regard our concepts of justice, good and evil, love and hate, the differences between the classic female and male brains and all variations in between.

# dear friends

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It has been some time since Gwill made the promise to herself to write a book about her son. Finishing her book, not only accomplished a goal she set in 1982, but it also reinvigorated her in a

sense. She has always been close to the Brain Research Foundation and other organizations she has championed over the years, but writing her book has reminded her why she became involved and what still needs to be done. The BRF has been grateful for Gwill's leadership and passion, and we are thankful that she has continued to play an integral part in the Foundation's efforts. In fact, we are extremely fortunate to have many long-standing trustees who continue to help steer the Foundation. As new trustees are elected to the board and executive committee, it has been valuable for those more recent to the BRF's vision to interact with trustees who have worked together over the years to promote the BRF and brain research. Our longevity has depended on it.

We are truly indebted to our trustees, our donors and our friends.

Sincerely,

Jene a Shar

Terre A. Sharma, Ph.D. Executive Director

# New President of the Brain Research Foundation



Nathan Hansen's life has been spent in and around the life sciences both personally and professionally. His father spent his career in the Medical Equipment/Device industry, and imparted

an appreciation for the many scientific advances in medicine being made through technology. Nathan has since become a Partner with Accenture, the world's largest professional services firm, focusing his work on helping to improve the operations of pharmaceutical and medical products companies.

Nathan comes to the Brain Research Foundation through a relationship with David Fishburn, a former Accenture Partner and current BRF Trustee, who made him aware of the group and its work. Nathan's family, like many others, has been touched by brain-related illness. Several family members have suffered from severe chronic depression and his extended family has also been touched by autism and Alzheimer's. These personal connections, combined with a professional passion for the life sciences, made the Brain Research Foundation a natural place for Nathan to get involved.

Nathan leads Accenture's global relationships with several large life sciences companies, and acts as overall Midwest Life Sciences leader for Accenture's practice. Having a long-standing commitment to the Chicago community, Nathan has been looking to channel energies back to the local community in order to make a difference. He has served on our Board of Trustees since 2005 and is currently serving as the President of the BRF.

# Excerpt from My Son's Name Was Fred

Gwill's Letter to the *Chicago Sun-Times* Personal View Gwill York Newman *Chicago Sun-Times*, Friday, October 16, 1981

### At Last, My Tormented Son Is At Peace

The notice of my son's death has appeared in this paper. The official cause of death was a ruptured aneurism, but the real cause was a crippling disease of the brain, known as chronic paranoid schizophrenia.

This devastating, cancer-like, biochemical imbalance of the brain is generally brought to the public's attention only in terms of sensational headlines when it is described as the illness that haunted "Son of Sam" of John Hinckley or John Lennon's murderer.

In fact there are over a million schizophrenics in this country who are horrendously victimized even though they never killed or harmed anyone. They constitute the majority of our mental patients who cannot be cured, and who, in so many instances, do not receive appropriate out-patient care upon returning to a community setting.

After more than three years working full-time as a professional volunteer in the field of mental health, I now write as a grieving parent.

As a parent whose grief is now acceptable and understood because a physical death has occurred, no longer having to grieve year after year in private or with a few understanding friends...

As a parent who watched a handsome, gentle, intelligent, maturing child lose all contact with reality and ultimately live like a hunted animal in dark, cold crawl spaces and attics, unable to care for himself in any way, unable to speak coherently, unaware of who he was or even that I was his mother...

As a parent who sought help all over the country and who, after expending all reasonable private financial resources to obtain the best available professional expertise, had to depend on state facilities for care...

As a parent who watched her son go through fourteen hospitalizations in less than five years, often suffering with him the indignities of the commitment process...

As a parent who had to listen while well-meaning friends and family offered suggestions that were ill-founded and only served to increase the feelings of helplessness and isolation...

As a parent who has known the frustration that comes when a new medication fails to work or when her son, coherent enough to be released, found that the community did not want him or understand him...

As a parent whose son was raped, physically beaten, repeatedly robbed and victimized when out in the community and not under twenty-four hour surveillance...

As a parent who has known great fear, sleeping with a knife under her pillow when her son's raging and hallucinatory anger turned violent—worrying that he might harm himself or others...

And as a parent who has suffered overwhelming guilt and watched a family torn apart by despair and accusations.

But now my son is dead. He died in his sleep in a mental hospital. Now all those who loved him can grieve and remember the days of his youth and gentleness.

No more will he beat his head bloody in an attempt to drive out the demons, no more will he have to suffer the terrible inadequacies of our knowledge and care, for he is finally at peace.

If those of you who read this will work to direct energy and funding toward research to someday eliminate this terrible disease, realizing that in the meantime there is an urgent need for humane, decent living conditions and care until a cure is found, then the parents who grieve in silence and those who suffer the fires in their minds will find release from their despair.

We ask for compassion and understanding, for only then can there be hope.

# brain matters



Dr. Morris Goldman, Department of Psychiatry, The University of Chicago

# **Brain Hormones in Schizophrenia**

Studies have shown that 15% of schizophrenics drink in excess of 3 liters of water daily. About 25% of these patients also exhibit water retention which leads to low blood sodium if mild, and life-threatening water intoxication if severe. When Manteno State Hospital asked The University of Chicago to help them manage a number of patients who were suffering from repeated episodes of water intoxication, Dr. Morris Goldman, then a resident and now an associate professor of psychiatry, offered to help. After developing a method for preventing the syndrome, Dr. Goldman and colleagues set out to characterize the mechanism of their water imbalance. The Brain Research Foundation funded these early experiments in which they determined that the antidiuretic hormone vasopressin (AVP), which causes the body to conserve water, was being secreted despite patients' marked water retention. The results were published in the New England Journal of Medicine, and hailed for their potential significance in an accompanying editorial.

They next confirmed that these patients, unlike others with schizophrenia, put out even more AVP when psychotic. The real issue remained, however, what could be overriding the inhibitory effects of the water retention? After methodically ruling out a number of explanations for this and the initial finding the investigators became interested in the observation that AVP secretion seems to worsen with psychological stress while in healthy controls it is suppressed. The part of the hippocampus responsible for this suppressive effect on stress hormone (cortisol) is one of the brain regions implicated in the pathophysiology of schizophrenia. Hence, Dr. Goldman tested whether hippocampal pathology produced the AVP defect by disrupting the inhibitory circuitry responsible for suppressing psychological stress responses. As predicted, AVP and cortisol responses to psychological but not to physical stresses were elevated; the part of the hippocampus which regulates this response was smaller; and other measures of hippocampal hormone regulation were similarly impaired.

AVP and cortisol are secreted from the same brain region (hypothalamus) as a closely related hormone, oxytocin. Oxytocin inhibits AVP responses to stress and along with AVP influences the social behaviors which are markedly impaired in many schizophrenic patients. AVP and oxytocin have been called the 'yin and yang' of neurohormones because of their opposite effects on behavior, and Dr. Goldman wanted to determine if oxytocin was diminished in association with the changes in hippocampal structure and function, and if this may have contributed to their social deficits.

Plasma oxytocin levels were measured during psychological stress and did not change in any of the groups, but were consistently lower in those with water imbalance. Furthermore, levels were predicted by the deficits in both hippocampal structure and function, and these patients also had greater social deficits. Social behavior and cognition are partly determined by the ability to accurately assess emotion in the facial expressions of others, and oxytocin enhances this capacity in healthy controls. Dr. Goldman set out to determine if diminished oxytocin levels predicted deficits in this domain, and found that it did for patients with and without water imbalance.

Deficits in social cognition and behavior are the most treatment resistant symptoms in schizophrenia, and are the major focus of new drug discovery. Intranasal oxytocin not only enhances the ability to identify facial emotions in normals, but appears to enhance trust in others, and reduce stress responses in social situations. Hence, Dr. Goldman has begun to assess if intranasal oxytocin reverses the defect in facial affect discrimination in these patients and others with schizophrenia, as the first step determining the possible efficacy of oxytocin therapy. This could be great help to a schizophrenic patient's everyday life, giving them the ability to better function in society.



- 1. Tom & Hope Reynolds
- 2. The Odyssey
- 3. Koko Taylor
- 4. Natalie Martinez, Patti Vasquez & Deborah Martinez
- Phyllis Beattie, Mary Beattie & Pat Koldyke
- 6. Michael & Suzanne Moskow

### Make Waves Benefit 2007

On Thursday, September 27, 2007, the Brain Research Foundation held its much-anticipated gala. The event took place on the privately chartered Odyssey Cruises with the Chicago skyline serving as our beautiful backdrop. Our theme, *Make Waves*, spoke to the Brain Research Foundation's mission of creating change and advancing brain research.

Co-chairs Pat Koldyke and Tom Reynolds organized a fabulous evening that raised money for such a wonderful cause—the Joseph P. Kennedy, Jr. Mental Retardation and Developmental Disabilities Research Center.



Top Three Raffle Prize Winners Jeanne Borchardt \$10,000 Cash

Ashley Pasen Diamond Necklace

John Mabie Romance Package (included wine, flowers, dinner and hotel stays) This year's gala benefited the Joseph P. Kennedy, Jr. Mental Retardation and Developmental Disabilities Research Center at The University of Chicago. The Center is one of the largest research centers in the United States committed to advancing the diagnosis, prevention and treatment of developmental disabilities, including autism, epilepsy and neurodegenerative diseases. The evening was picture perfect—unseasonably warm and wonderful. During cocktail hour, guests participated in a raffle and a silent auction. The silent auction had fantastic items, including an iPhone, a Marc Jacobs handbag and a Raymond Weil watch. We were happy to award the 1st place raffle prize of \$10,000 to Jeanne Borchardt.

The fun continued as Mistress of Ceremonies, NBC5's Natalie Martinez, charmed the audience and kept the evening moving. After dinner, we were privileged to experience a fiery performance by the Grammy Award winner and Chicago legend, Koko Taylor & Her Blues Machine. She certainly proved she is still the undisputed Queen Of The Blues.

We hope everyone enjoyed the evening as much as we did. We look forward to seeing you at our next benefit.



# **Annual Seed Grants**

Since the Fay/Frank Seed Grant Program's inception in 1981, the Brain Research Foundation has awarded over \$6.9 million in seed grants. This year, the Foundation will award a total of \$400,000 to deserving scientists studying brain research. In addition, the Women's Council of the BRF will award its annual seed grant of \$25,000 to a female scientist training in the field of neuroscience.

Supporting groundbreaking research in neuroscience has been the sole function of the Seed Grant Program. The program represents the most important work the Foundation does: funding the pilot stage of innovative ideas and promising investigations that drive advances in our knowledge of how the human brain functions. Seed grants provide start-up money for innovative projects that have the potential of obtaining funding from the National Institutes of Health or other outside sources. The grants enable scientists to compile preliminary data on a new topic, or make collaboration possible across scientific disciplines. Many times, the grants allow scientists to conduct pilot research studies in areas outside their usual fields.

The Brain Research Foundation makes this meaningful investment each year and each year the impact is remarkable. As envisioned by the Brain Research Foundation founders, the seed grants have brought greater funding to the scientists who have received them. For every \$1 the Foundation has invested in new ideas, researchers have attracted over \$25 in additional funding from the National Institutes of Health and other outside sources.

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#### Seed Grant Success Stories

- •Improvement of neural prosthetic technologies to develop a brainmachine for paralyzed patients that will enable them to someday control a prosthetic limb with their brain
- •Development of a sensor to measure pressure and blood flow in the brain to aid in diagnosis and recovery from severe brain injuries such as stroke
- •New pre-surgical approach for epilepsy patients that may someday replace current painful surgical procedures
- •Treatment strategy to manipulate the immune system to target cancer cells and destroy brain tumors

For more information on the Brain Research Foundation, please call (312)759-5150 or visit our website at www.brainresearchfdn.org