

High Expectations and The Right Team

by Perry Green, University of Louisville student

- “Backpack...Check”
- “Assignment Notebook...Check”
- “Math Folder...Check”
- “English Folder...Check”
- “Social Studies Folder...Check”

Like many, that was my daily routine before heading off to school. Quite honestly, even at age 22, it continues to be my routine. My name is Perry Green and I have Attention Deficit/Hyperactivity Disorder (ADHD). Currently, I am finishing my undergraduate degree at the University of Louisville, where I am a Pan-African Studies major. I was diagnosed with ADHD when I was seven years old.

When I finish my degree, I plan to go on to graduate school, and after that, who knows. What can I say? I have ADHD. One thing I know for sure is that my future is boundless.

As I write this article, I am staring at the paper bomb that has exploded over my desk and in my work area. My bedroom is a mess and my backpack looks like I am still in elementary



Perry Green

school. At one point, medical experts suggested that people “outgrow” ADHD. I beg to differ. Everyday has its challenges, victories, and ADHD moments, like when I forget to grab the right notebook for class or miss the bus because I was on Facebook or MySpace.

I am always asked by parents of younger children with ADHD, “how is it that you are so successful and able to manage your ADHD?” Depending on how jovial or serious the person is,

I usually respond in one of two ways — “you know I really do not know ... some days I wonder” or “my parents.” The correct answer is “all of the above and then some!” One of the most important lessons I have learned about successfully managing my ADHD is that it takes a team. If it were not for the countless teachers, my parents, and other professionals, I would not have made it to college, let alone finished high school.

One of the other elements of successfully managing ADHD in my life is lining the pockets of Silicon Valley businesses ... technology has been a huge help

to me. From the time I was 15, I have consistently used a PDA (personal digital assistant) to help me with appointments, school assignments, managing my time, and staying organized. However, if it were not for my parents, I would not be where I am today. One of the most important things that my parents did for me was to EXPECT MORE! It saddens me that in some households, schools, and communities — ADHD is used as an excuse. My parents never allowed me to use ADHD as an excuse for anything. I am not saying that my parents were precision-driven drill instructors (although at times I saw them that way), but they knew when something challenged me and yet, still always expected me to

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A Message from the Executive Director

PARITY AT LAST. WE ARE CLOSE.

In the last issue of *VOICES* I talked about tremendous legislative victory in the Congress when, the House and Senate successfully overrode the President's veto of legislation (HR 6331) making critical reforms and improvements to the Medicare program for participants living with mental illness.

As I write this letter, we are very close to another huge legislative victory. NAMI has been battling for decades to pass a comprehensive mental health parity law for health insurance coverage in the private marketplace.

The passage of this comprehensive parity legislation will benefit thousands of American citizens with serious mental illness. It will mean, at last, equity for mental illness and substance abuse coverage with respect to numerical limits on inpatient and outpatient services. It will end the arbitrary discriminatory limits on inpatient and outpatient coverage that do not also apply to medical-surgical coverage.

This legislation will also create equity for mental illness and substance abuse coverage with respect to financial limitations. It will ban higher cost sharing, deductibles and out-of-pocket limits that do not also apply to medical-surgical coverage. This legislation also creates a parity standard in the federal ERISA law thereby covering the 82 million Americans in ERISA self-insured group health plans with 50 employees or more that are now exempt from complying with the 42 state parity laws.

We are extremely grateful for the efforts of advocates all across the country that e-mailed, wrote and called their Senators and House members. Your advocacy has made a tremendous difference!

While the wars in Iraq and Afghanistan no longer dominate the evening news, NAMI recognizes that mental health is the second largest area of illness (after orthopedic problems) for which veterans of Iraq and Afghanistan seek



treatment in Veteran's Administration (VA) facilities. To begin to respond to this crisis, NAMI has recently signed agreements with the AMVETS to begin to offer our family services through their posts. We have also signed an agreement with the Veteran's Administration to bring NAMI's Family to Family programs to VA facilities across America. Our Veteran's website has been enhanced and a new PTSD education pamphlet is in the works.

We are now in our fall NAMI Walks season. Communities all over America are participating in annual NAMI Walks. These Walks boost the visibility of mental illnesses enabling ever more people to see them as illnesses like any other. NAMI will run 74 Walks in 2008. Please consider walking in a NAMI Walk near you. More than 200,000 walkers have already participated in communities across America. An independent survey declared that NAMI Walk was one of the fastest growing walks in America. You can find the NAMI Walk nearest you by visiting our

website at www.nami.org/walk.

Your support has allowed NAMI to pursue these and other initiatives. This success is due in some part to your generous support of our work. We hope this success will inspire and encourage your continued support of NAMI. Enclosed is a donation card and envelope for your continued support of NAMI.



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do my BEST. I was always frustrated with teachers who did not have similar high expectations for me.

The other key factor for me in successfully managing my ADHD was to find and discover my passions. All too often, young people with ADHD hear about how awful they are, or about all the things they do not do well or struggle with. I deeply believe that despite the fact that these negative attitudes are the norm — it should be the other way around. When I was a freshman in high school I began debating, it was my passion, and

something that I became very good at. That was my “ticket out” of always hearing about all the things I could not do well.

If there is one thing that I could say to those interacting with children and teens, especially those with ADHD, it would be to celebrate their successes and to focus on their victories and the obstacles they have overcome, rather than the on-going roadblocks and challenges they so often face. Not to say that people do not need to work on their challenges, but trust me, we already know our failings and do not need to be reminded of them.

I know that I will continue to face many of the same challenges as an adult with ADHD that I did as a child and teen. Just one look at my mother, who also has ADHD, convinces me of that. But I also know that the great foundation that I have in my “ADHD management team,” which includes my family, my teachers, and my doctors, is the support I need as roadblocks are thrown into my path. The support of my team is what gives me the drive and desire to want to become an advocate for other people facing challenges in their lives.

Trick or Treat? Fighting Stigma

by Bob Carolla, NAMI Director of Media Relations



NAMI’s “StigmaBusters” program is nationally respected for leading protests and educating news, entertainment, and advertising media about inaccurate and offensive stereotypes of people living with mental illnesses.

Founded over a decade ago long before most people were plugged into the Internet, the program today consists of a network of more than 20,000 people who receive monthly StigmaBuster Alerts by e-mail. They stand ready to send letters, faxes and e-mail messages to protest unfair media portrayals.

StigmaBuster battles don’t necessarily change attitudes, but they raise awareness. Some-

times they change behavior. Companies like General Motors (to name just one) often would rather drop a television commercial than con-front public controversy, or at least think twice the next time an ad agency proposes a stigmatizing or insensitive portrayal.

Even better, protests can lead to dialogue and partnerships. At the local level, radio stations, advertisers, or other sources who intended no harm sometimes are recruited as NAMIWalk sponsors.

Unfortunately, October is a peak time for StigmaBusting skirmishes, because of the Halloween attractions such as “haunted insane asylums” that demean people with mental

illnesses and perpetuate violent stereotypes.

Local NAMI leaders find themselves negotiating with schools or civic sponsors to modify themes or at least promise not to offend in future years. Affiliate press releases or letters to editors focus community attention on a key issue—stigma—that the U.S. Surgeon General has declared to be one of the greatest barriers to people seeking help when they need it.

Fighting stigma is not about “political correctness.” It’s about individual dignity and public health.

To sign up for NAMI StigmaBuster Alerts, visit www.nami.org/stigma.

Medication, Devastation, Tooth Preservation

A Call for Action

I am a dental hygienist and was a caregiver for my twenty-four year old son affected with severe mental illness (SMI) until his passing. Not only did SMI drastically change the overall quality of life and general health of my son, it had a detrimental impact on his oral health. Within one year of my son's diagnosis, after taking the prescribed medications, his teeth began to disintegrate. Because his medications caused him to have dry mouth coupled with the negative symptoms of his SMI, his teeth developed severe decay that led to over \$15,000 in dental reconstruction. We were fortunate that we could provide dental treatment for him, whereas many others with SMI are not that fortunate and consequently lose their teeth.

I presented an oral health booth exhibit at the 2008 NAMI Annual Convention in Orlando, Florida. My goal was to create awareness and understanding for the need to professionally manage patients dentally that face this difficult journey in life. I was shocked with the overwhelming response and appreciation I received from the consumers and mental health care professionals. The attendees were very surprised to learn that so many medications prescribed for the mentally ill cause dry mouth and lead to tooth destruction. They received information about numerous products, over the counter and prescription, to combat oral dryness and cavities. They also learned that oral health has a big impact on general health. The attendees all agreed when surveyed, that consumers need to have dental health care in the

fore front as part of their total health care treatment. Saliva is a precious body fluid. Over 700 prescription medications decrease saliva flow. They include: antipsychotics, antihistamines, antidepressants, anticholinergics, mood stabilizers, etc. Adequate salivary flow and its unique composition of proteins are essential to the maintenance of oral tissues (DePaola). Many functions have been ascribed to saliva. A very important function (not widely known) is the acid buffering capacity essential in maintaining the balance of the demineralization and remineralization process of calcium ions and phosphates that ensures the integrity of the tooth surface. Without this buffering capacity the tooth enamel and root surface will demineralize or disintegrate very rapidly. Saliva also protects the oral mucosa with lubricants, rinses away food debris, facilitates taste, provides protection from invasive pathogens and aids in the break down of food – the beginning of digestion.

Tooth preservation is not the only reason to promote good oral health. Oral infection caused by poor oral health, such as gingivitis and periodontal disease, can have an adverse effect on other organs of the body. A growing body of research is discovering a two-way relationship between oral health and general health for health issues such as: endocarditis, coronary artery disease, stroke, respiratory disease, diabetes, and pregnancy issues such as, low



Lisa Stillman Knapp

birth weight and premature birth. These discoveries support interdisciplinary patient management for all, but especially for the consumer that manages mental health symptoms, oral hygiene difficulties and dry mouth. All of which cause a host of painful and irreversible oral damage.

Dental professionals need to be directly involved with the consumers concerning oral health care to ensure total care. Mental health professionals and caregivers need to include and monitor oral health as part of the patients overall health assessment. Consumers, when stabilized, need to be able to resume their lives without dental pain and feel confident about their smile.

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References: 1) DePaola DP, *Saliva The precious body fluid*, JADA, May 2008; Vol. 139: 5S-8S.; 2) Stookey GK, *The effect of saliva on dental caries*, JADA, May 2008; Vol. 139: 115; 3) Scientific American Inc, *Scientific American Presents: Oral and Whole Body Health*, 2006; 4) Zunt S, *The Importance of Saliva*, Dimensions of Dental Hygiene, January 2006; Vol. 4:26-29.

NAMI has recently partnered with the Special Needs Alliance (SNA), a national non-profit organization of attorneys dedicated to the practice of public benefits and disability law. This partnership will enable us to provide our members with the most current and reliable information on special needs planning.

The following is part of our ongoing series of articles on special needs planning issues authored by members of the SNA. To learn more about a special needs trust go to www.nami.org/specialneedstrust or call Darcy Taylor at 703-516-7992. To locate an SNA member attorney near you, please visit www.specialneedsalliance.org.

Third-Party Special Needs Trusts

by Bernard A. Krooks, Littman Krooks LLP
Member, Special Needs Alliance

Perhaps one of the biggest concerns for parents of children with special needs is how to provide for their child when the parents are no longer around. While there is no perfect replacement for parents' love and care, some legal and financial planning methods can alleviate those concerns.

Consider this family's situation:

John and Sally have three adult children: Charlie, Emily and Sam. Charlie and Emily are independent and healthy; however, 37-year-old Sam has a mental illness and lives with John and Sally. John and Sally understand that Sam will need a home, income and a support system provided for him for the rest of his life.

Without appropriate estate planning, Sam will inherit from his parents. Because Sam is not capable of managing financial assets, the court would most likely appoint a guardian who would have to request distributions to be made for the benefit of Sam and account to the court each year. Moreover, the assets that Sam receives may preclude him from obtaining certain types of governmental assistance benefits without the assets being spent down on the cost of his care.

John and Sally are considering leaving all their assets to Charlie and Emily who have promised to take care of Sam. Although this may seem like a good arrangement, it has serious problems that could imperil Sam's security—no assets are legally protected for Sam, who may live a long time. Despite the best of intentions, Charlie and Emily



Bernard Krooks

may not live up to their commitment due to financial problems, becoming disabled themselves, getting divorced or dying.

A good solution is the creation of a *third-party special needs trust* (also known as a supplemental needs trust) for Sam. The SNT would be designed to hold Sam's inheritance. It needs to be carefully drafted so that the assets in the trust can be used to enhance Sam's lifestyle without causing him to lose his needs-based benefits. If an intended beneficiary has a disability and is not capable of managing his or her own money, then this benefi-

ary may also be supported in the community through a variety of means-tested entitlement programs, such as Supplemental Security Income (SSI) and Medicaid. In most of programs, the beneficiary's receipt of funds will terminate the beneficiary's participation in the program. SNTs are designed to allow the beneficiary to maintain eligibility for most means-tested programs, while still allowing the trustee to access trust funds to pay for goods and services that enhance the quality of the beneficiary's life.

Of course, there is no one perfect solution that works just right everyone. However, it is important to remember that in creating a third-party special needs trust; you must make sure that it conforms to the applicable laws, while maintaining maximum flexibility to improve the quality of life of the child with special needs.

“UNMASKING MENTAL ILLNESS”

NATIONAL ALLIANCE ON MENTAL ILLNESS

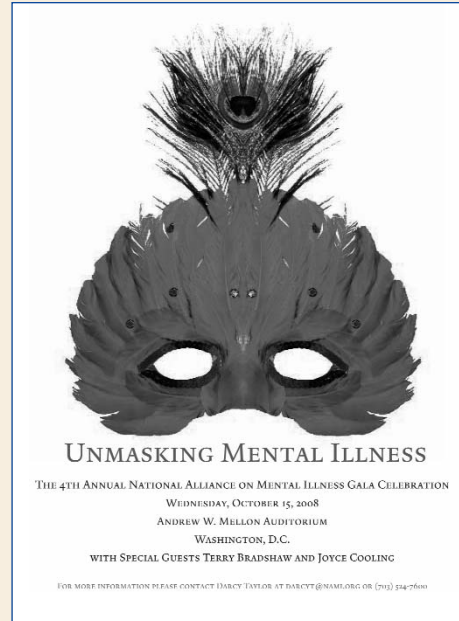
FOURTH ANNUAL DINNER AND PRESENTATION OF THE MIND OF AMERICA SCIENTIFIC RESEARCH AWARD

CO-CHAIR: Kay Redfield Jamison, Ann Pincus

DATE: Wednesday, October 15, 2008

LOCATION: Andrew W. Mellon Auditorium
1301 Constitution Avenue, N.W.
Washington, D.C.

ATTIRE: Informal (Business/Cocktail)



NAMI will host its 4th Annual Gala celebration, “Unmasking Mental Illness” on Wednesday, October 15, 2008. The evening will begin with a cocktail reception, followed by a seated dinner and the presentation of the Mind of America Scientific Research Award to a scientist whose efforts have resulted in ground-breaking research that has significantly contributed to a better understanding and treatment of mental illness.

Proceeds from the evening will benefit the programs of NAMI, their dedication to eradicate mental illnesses and improve the quality of life of all whose lives are affected by these diseases.

Founded in 1979, NAMI today works to achieve equitable services and treatment for more than 15 million Americans living with serious mental illnesses. Thousands of volunteers participate in local and state affiliates to provide education and support, combat stigma, support increased funding for research, and advocate for adequate health insurance, housing, rehabilitation, and jobs for people with mental illnesses and their families.

Watch your mail in the coming weeks for your Leadership Alliance renewals and your chance to become a proud member of this amazing group of people.

We are currently in the process of cleaning our database – if you have a change of address, your name is misspelled, you are receiving duplicate mailings, or any other changes you might need, please let us know by sending an e-mail to data@nami.org or calling 1-800-950-6264.