

**Surviving and thriving**  
With a movement disorder

**Elusive diagnosis**  
New hope for PBA sufferers

**Awareness is critical**  
Recognizing a brain aneurysm

**MEDIA  
PLANET**

June 2011

# BRAIN HEALTH



## LIVING WITH NEUROLOGICAL ISSUES

**Dr. Julian Bailes** discusses new advancements  
in treating traumatic brain injuries

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## CHALLENGES

Brain injuries and neurological issues have affected millions of lives, but research and **the power of public awareness** are making headway every day.

## Spotlight on our most vital organ

It can happen almost any place, at any time. It can be caused by falling off a bike or slipping in a bathtub. It can take place on the playing field or the battlefield. It can cause lifelong problems with memory and thinking impairment, as recently reported by pro football players. And it can kill, as we witnessed with actress Natasha Richardson's tragic skiing accident.

Traumatic brain injury, or TBI, is caused by a sudden, extreme jolt to the head. It can happen when an unprotected head hits the curb during a cyclist's fall. When two helmeted heads collide during a football game or when the skull is punctured as a bullet enters the brain. It can also happen when the brain is shocked by a bomb blast, as many soldiers have experienced in Iraq and Afghanistan, where TBI is known as the "signature wound" of combat.

Brain injuries suffered by our soldiers and concussions experienced by athletes have helped raise public awareness of these traumas. The National Football League (NFL) has changed rules on contact with the head, and now requires a neu-

rologist to be present at each game to tend to players who may have suffered a concussion. State legislatures are passing laws to protect child athletes who have received a head injury on the field. Athletic leagues—from juvenile to professional—are taking steps to ensure players have time to recover before resuming practice or play.

**Making a difference**

The American Academy of Neurology has been at the forefront in helping address TBI treatment and prevention issues, from working with Congress to pass legislation requiring proper care for military veterans with TBI, to issuing guidelines and tools for recognizing sports concussion and preventing further injury. We are pleased to have been invited to join with the Brain Injury Association of America, Think First!, Congress of Neurological Surgeons, the AANS, NASHIA, and the Sarah Jane Brain Foundation to produce this educational supplement with Mediaplanet.

One out of every six Americans is living with a brain disorder, whether it be TBI, movement disorders, epilepsy, migraine, stroke,



**Bruce Sigsbee, MD, FAAN**  
President, American Academy of Neurology



"There are more than 600 brain disorders treated by neurologists... addressing these illnesses is crucial, as they cost our nation as much as \$400 billion a year."

Alzheimer's disease or Parkinson's disease. There are more than 600 brain disorders treated by neurologists, who are physicians with specialized training in diagnosing, treating, and researching neurologic disorders. Addressing these illnesses is crucial, as they cost our nation as much as \$400 billion a year. To find a neurologist near you or donate to further research on preventions and treatments of brain disorders, visit [www.aan.com/patients](http://www.aan.com/patients).

We hope the stories in this supplement improve your understanding of how traumatic brain injury can be recognized, treated, and—perhaps most importantly—be prevented. Please share this information with loved ones and friends.

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TIP

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TO MAKE A  
DIFFERENCE



WE RECOMMEND



**Paulette Hicks**  
An active brain is a healthy brain!

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**MEDIA  
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## Merz Pharmaceuticals Joins Cervical Dystonia and Blepharospasm Patient Advocates To Launch Make Your Mark

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**The Make Your Mark Campaign sponsored by Merz Pharmaceuticals, LLC, is designed to inspire cervical dystonia and blepharospasm patients and their families, and to raise awareness of and build advocacy for these often debilitating conditions.**



Visit [www.MakeYourMarkCampaign.com](http://www.MakeYourMarkCampaign.com) to learn more and read the inspiring stories of people living with cervical dystonia or blepharospasm:



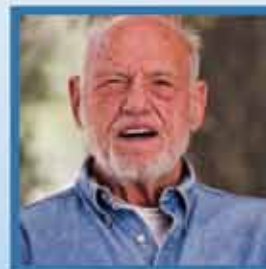
**Dawn Brinkley**

2010 Mrs. North Carolina and volunteer  
Living with cervical dystonia since 2004



**Hallie Neill**

Opera singer actress and writer  
Living with cervical dystonia since 2007



**Alfred J. (A.J.) Deguo**

Support group coordinator  
Living with blepharospasm since 1994

## INSPIRATION

TIP

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USE YOUR  
EXPERIENCE  
FOR POSITIVE  
CHANGE

## A NEW HORIZON

Movement disorders are often misdiagnosed, but advocacy efforts by survivors are changing the conversation.

PHOTO: ISTOCKPHOTO.COM

**Question:** How do you react when a disorder suddenly changes everything about your life?  
**Answer:** You take it and use it as fuel for something good.

# When a diagnosis becomes a calling

## HOW I MADE IT

"That foot cramp that makes you hop out of bed in the middle of the night? Imagine that in your neck or shoulders, and there's nothing that can make it stop. Imagine that 24 hours a day, 365 days a year."

### A new way of life

That, according to Dawn Brinkley, is the reality of cervical dystonia, a rare neurological movement disorder that causes sustained, involuntary muscle contractions in the neck and has no cure.

Brinkley received her diagnosis in

2004 at the age of 32, after visiting 12 different doctors over a period of 12 months. Though the disorder is roughly as prevalent as Parkinson's, a shortage of awareness often leaves those afflicted feeling educationally alone, an experience that for a long time prevented Brinkley from moving forward.

### Making the best

"It's really hard to see the positives when you're in pain, but I found that when I change my attitude I change my outcome," says Brinkley. Her change in attitude led her to become a tireless defender for a number of causes, bring-



"I found that when I change my attitude I change my outcome."

Dawn Brinkley

ing light into the lives of many in need. Recognizing a desperate need for further cervical dystonia awareness, she took up one of the most unlikely platforms for a person with a debilitating movement disorder to spread the word: beauty pageants.

### Taking the stage

Though she'd never had any interest in pageants before, the challenge of the meticulous poses and flawless presentation, all under the scrutiny of the bright lights and judges, seemed like an irresistible way to prove that she was not a prisoner to her condition. And in

2010, Brinkley was crowned Mrs. North Carolina United States, a privilege that has since given her countless opportunities to advocate for cervical dystonia.

Says Brinkley: "There will be days where I won't be able to get out of bed, but cervical dystonia has brought so many experiences to my world, it's brought people I never thought I would meet, and it's made me a person I never thought I would be. And it's all because of this diagnosis."

STEVE ETHERIDGE

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NEWS

# Making progress on brain injuries

## Despite being intensely difficult to treat, new efforts are looking to take the trauma out of brain injuries.

The human brain, buoyed in cerebral spinal fluid, has space to move around, meaning that not only can it sustain injury through impact but also through the inertia of acceleration. Ever vulnerable, the risk of traumatic brain injury is not to be underestimated.

## Dangerous games

Sports alone account for as many as 3.8 million traumatic brain injuries a year, many coming by way of concussion. Public awareness of the lasting danger of concussions has escalated in recent years due to the discovery of chronic traumatic encephalopathy, or C.T.E., the degenerative disease found in athletes who have sustained repeated concussions.

Alarming, athletes who have

suffered multiple concussions are three times more likely to suffer clinical depression. Retired NFL players suffer Alzheimer's disease at a 37 percent higher rate than the general population, and they're five to 19 times more likely to receive a dementia-related diagnosis.

## Improving measures

In response to these realities, concussion protocols have been beefed up all throughout professional sports, with stricter guidelines emerging regularly.

"At every level of professional of sports, there have been significant, important, and sweeping changes that have led to better recognition of concussions," says Dr. Julian Bailes, chairman of neurosurgery at West Virginia University Hospitals and neurological consultant to the NFL Players' Association.

## Harming the most vulnerable

"Unfortunately, while sports-related brain injuries have seen improvement, some of the most tragic traumatic brain injuries have escalated at a devastating rate."



**Dr. Julian Bailes**  
Chairman of Neurosurgery, West Virginia University Hospitals; Neurological Consultant to the NFL Players' Association  
PHOTO: WVU HEALTHCARE AND WVU HEALTH SCIENCES

Unfortunately, while sports-related brain injuries have seen improvement, some of the most tragic traumatic brain injuries have escalated at a devastating rate. During the recession, instances of babies being hospitalized with non-accidental head injuries more than doubled, frequently due to the form of child abuse known as shaken baby syndrome.

"We know that times of increased stress may be more dangerous for babies," says Dr. Robert Block, president-elect of the American Academy of Pediatrics. "It makes sense that in a recession, where there are all kinds of very stressful situations, we would see an uptick in these kinds of injuries."

## New horizons

Traumatic brain injury accounts for some 50,000 deaths in the U.S. each year, yet despite this figure there are still no federally approved drugs specifically for its treatment.

It has been observed, however, that females do better with brain injuries than men, and researchers have cornered progesterone, a hormone commonly associated with pregnancy, as a reason for this.

"We think that progesterone has a potential to reduce brain inflammation, brain swelling, and brain cell death from traumatic brain injury," says Bailes.

An important study, called SyNAPSe, is underway to test the efficacy of progesterone on brain injury in both males and females. Clinical data on the neuroprotective properties show strong promise that progesterone treatments—formulas delivered via intravenous infusions—could be the first significant fix for traumatic brain injury. Such a step is necessary for advancing the care of those in critical need.

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## NEWS

## AN ACTIVE BRAIN IS A HEALTHY BRAIN!

**How does engagement in activities such as games help the brain maintain optimal function?**

Playing games can be great exercise for your brain and help strengthen your brain's cognitive reserve. Cognitive reserve acts as a protective buffer and is created by active engagement in stimulating intellectual, social and physical activities. This buffer helps the brain to fend off symptoms of cognitive decline. Our brains crave novelty, complexity and variety, and playing games provides that stimulation. Engaging in new games that challenge cognitive areas such as critical thinking, memory or word skills promotes the creation of neural pathways that help maintain and improve brain function.

**What is a critical stage in a person's life at which s/he should consider implement-**

**Paulette Hicks**  
Marbles  
BrainCoach

**ing critical thinking exercises into a daily routine?**

Exercising critical thinking skills is important from early childhood through late adulthood. However, it is beneficial to bolster these skills before you see symptoms of age-related decline. The brain's ability to take in information and process it quickly and accurately starts to slow in our thirties. So, it could be said that early and middle adulthood are important stages to strengthen critical thinking skills. Another crucial stage could be after retirement. When people leave the workforce, opportunity for mental stimulation is often less available. Being proactive and implementing exercises that maintain and strengthen critical thinking are vital to cognitive health.

# The effort to control uncontrollable emotions

**An unusual disorder is receiving attention after a century on the backburner.**

There are few disorders as profoundly frustrating as pseudobulbar affect. Characterized by involuntary, frequent, and uncontrollable laughter or crying regardless of how one feels, PBA affects as many as 2 million Americans and is associated with neurological diseases like Lou Gehrig's disease, MS, and Alzheimer's.

"This condition is socially disabling," says Dr. Jonathan Fellus, director of brain injury services at the Kessler Institute for Rehabilitation. "Patients can't go out, they're unpredictable. If they have the capacity to work, they can't."

Despite having been recognized

as a condition for over 100 years, until recently there was no existing FDA-approved drug for the treatment of PBA, and patients were commonly misdiagnosed as being depressed.

**Reason for optimism**

Yet in January, a prescription medicine called Nuedexta was made publicly available. In a study on its effectiveness, over half of the patients involved experienced total resolution of symptoms by the last two weeks of the trials, signifying hope after a long wait for PBA sufferers.

"I've had patients within one or three doses experiencing immediate benefits," says Dr. Fellus.

Nuedexta, which is a combination of two existing drugs, one which is found in cough medications and

another that is used to treat malaria, is only the beginning of an awakening in the treatment of PBA.

"This is an under-diagnosed, underappreciated, undertreated condition," says Dr. Fellus.

"But now you're building towards a tipping point where people recognize that what they thought was something else is really pseudobulbar affect."

Doctors need to be more adamant about screening for and recognizing PBA, notes Dr. Fellus, but awareness seems to be spreading throughout the medical community. In the meantime, those who suffer from PBA can have some peace of mind about better days to come.

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## PLAY YOUR WAY TO A HEALTHIER BRAIN

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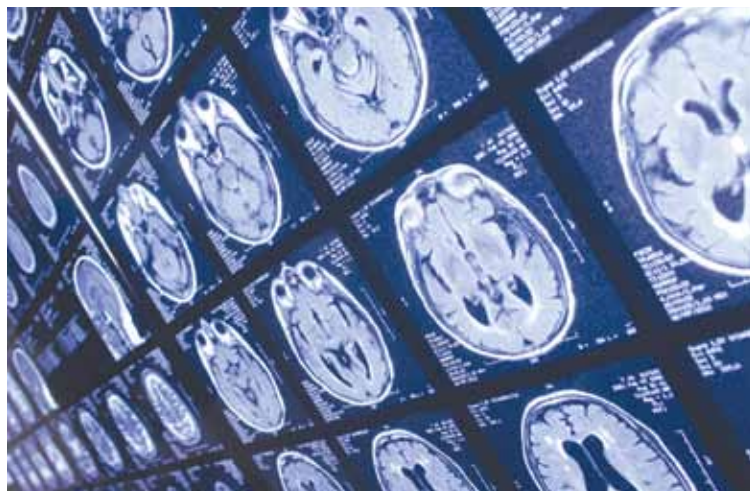
# INSIGHT

# Early detection and emergency care of aneurysm rupture is critical

**About one percent of the US population has a brain aneurysm.**

Further, every year approximately 30,000 Americans rupture a brain aneurysm with potentially devastating consequences, including sudden death in about 20 percent of cases. Eighty percent of patients, however, may have a chance of survival if they reach expert care in time. For this reason, it is critical to understand the risk factors, signs and symptoms of aneurysm rupture, so you can seek immediate life saving medical attention by calling 911.

Brain aneurysms are outpouchings on brain vessels which usually form and grow silently over many years until they rupture or cause symptoms related to com-



**KNOW YOUR RISKS** Don't hesitate to take care of your brain. PHOTO: ISTOCKPHOTO.COM

pression of adjacent brain tissue or nerves. The most telling symptom of aneurysm rupture is a sudden onset severe explosive headache, which you should assume to be the

result of an aneurysm rupture until proven otherwise. Since aneurysm re-rupture can be catastrophic in over 50 percent of cases, the most important goal of initial manage-

ment is to prevent re-bleeding. The ER team also focuses on management of brain pressure and medically stabilizing the patient. With good care, over half of patients can have an excellent outcome.

Given the potentially devastating impact of brain aneurysms, recent research has focused on prevention and screening. The most important preventable risk factor is smoking, which dramatically increases the risk of brain aneurysm rupture. Other risk factors include having two family members with a brain aneurysm, strong family history of aneurysm rupture, and presence of connective tissue diseases such as polycystic kidney disease and Marfan's syndrome. Risk of rupture depends on a number of factors including size, shape, genetics, and

presence of risk factors. Screening for brain aneurysms can be undertaken safely with magnetic resonance angiography, and there are a number of treatment options available, including observation, microsurgical clipping, endovascular coiling and stenting. For more information, visit [www.cns.org](http://www.cns.org).

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## CLINICAL TRIAL



drug treatment for tbi

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## NOT GETTING THE RESULTS YOU'RE LOOKING FOR?

## HELP CHANGE THAT.

The fact is that there are no drug treatments that have been shown to improve the outcomes of traumatic brain injury patients. But there is hope.

BHR Pharma is enrolling patients in **SyNAPSe®**, a global Phase 3, multi-center trial to evaluate the effectiveness of BHR-100 intravenous progesterone infusion. In U.S. and international studies, progesterone has shown promising results in improving overall recovery and decreasing mortality, with a good safety profile.

**SyNAPSe: the Phase 3 clinical trial designed for FDA approval of progesterone in TBI.**

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- Enroll patients with a GCS score of 4 to 8
- Begin treatment no later than 8 hours after injury
- Intravenously administer progesterone for 120 hours

SyNAPSe is endorsed by the American Brain Injury Consortium and the European Brain Injury Consortium

Learn more at [synapse-trial.com](http://synapse-trial.com).

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## Expressing emotions shouldn't be left to chance

- People with pseudobulbar affect (PBA) suffer sudden, involuntary outbursts of crying or laughing throughout their day
- PBA can occur in people with an underlying neurologic condition—such as Lou Gehrig's disease (ALS), multiple sclerosis (MS), stroke, or traumatic brain injury
- Though it may sometimes seem like it, a person with PBA is not alone. More than a million Americans suffer from the condition

If you or someone you care for shows signs of having PBA, talk to your doctor or visit [PBAinfo.org](http://PBAinfo.org). You can also share your PBA experiences at [facebook.com/PBAinfo](https://facebook.com/PBAinfo)