

BRAIN WAVES

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Upcoming Events

- **Nov. 4, 6:30 p.m.**, Regular Meeting, University Hospital
Paul E. Newman, PdD., Director, Behavioral Health, Drake Center
- **Dec. 2, 6:30 p.m.** Holiday Social, University Hospital
- **Jan. 16**, Winter Party, Indian Creek Apartments Clubhouse

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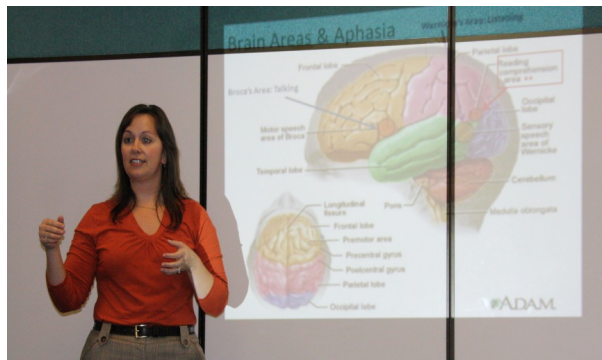
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Survivors are helping others

This has been another active quarter for the Tri-State Aneurysm Support Group.

Following a successful symposium in April at the University of Cincinnati, members met for a summer picnic in Fort Thomas and a series of monthly meetings that included a compelling story from the family of one of our members, invigorating discussions involving the interaction between caregivers and survivors, and a terrific presentation to a packed house about the speech problems that are common among those of us who have survived brain injuries.



We'll offer highlights of these activities in this issue of Brain Waves, along with stories about the University of Cincinnati's remarkable success in security stimulus funds for aneurysm research and the inspiring story of a national-caliber athlete from Greater Cincinnati who is recovering from a brain aneurysm and hopes to resume her collegiate career.

The Tri-State Brain Aneurysm Support Group was established in 2002 to help survivors of brain aneurysms, as well as family members and friends involved with their care. It is a volunteer-driven, non-profit organization. The group generally meets on the first Wednesday of each month (except January and July) at 6:30 p.m. at University Hospital.

Symposium will be bigger, better in 2010

Members of the Steering Committee of the Tri-State Brain Aneurysm Support Group, Inc. voted Oct. 21 to partner with the University of Cincinnati's Neuroscience Institute to produce a symposium in the spring of 2010.

As envisioned by the steering committee and representatives of the Neuroscience Institute, the one-time agreement would enable a larger and more robust presentation than those offered in past years by the Support Group alone.

In addition to brain aneurysms, the symposium is likely to address other cerebrovascular diseases and is expected as well to include presentations that will carry continuing education credits for health care providers.

But the agenda will be designed in a way that concentrates presentations related to brain aneurysm in one portion of the day. That way, steering committee members felt, members of the support group could stay for the portion of the symposium most likely to be of interest to them. As they were able and interested, they could, of course, stay for other parts of the program as well.

The question now for members of the Aneurysm Support Group is this: What specific topics would you like to see on the agenda at the symposium?

If you have any ideas, please forward them to Sandy Ross, secretary of the Steering Committee, at sross21@fuse.net.

Cool start, warm finish for summer picnic

The Seventh Annual Tri-State Brain Aneurysm Support Group, Inc. Picnic at Highland Hills Park in Fort Thomas started out "cold" due to the weather, but soon heated up with the arrival of the grill!

In the absence of our scheduled chef, Linda Reller, member Bob Kusssmaul graciously agreed to step in and take over grilling duties. He toasted the hot dogs and roasted the steaks liked a pro, though they turned out to look – and taste – a lot like hamburgers. All teasing aside, Bob did a great job!

Once the grilling was complete and all the 'food to share' was set out, Charlene Taylor, survivor, offered a very special blessing for all before dinner. The food brought by everyone was plentiful and tasty. And, unlike the winter social, there were desserts.

Courtesy of Chad Gillum, many raffle tickets were sold. The raffle was a big hit, thanks to Evelyn Ross (Sandy Ross' mother) who kindly embroidered flowered hand towels and a set of dragonfly pillowcases. Additionally, the raffle included four tickets to a September Reds' game, with food and beverage



ages added. These tickets were donated by Kristin Gillum's father. They were won by caregiver Greg Mullins, the towels by survivor Pat Varney, the pillow cases by guest Anita Ping.

The "split the pot" also was a hit. This and our raffle have been our group's only fund-raising for this year. Survivor Nancy Blakeman won the "pot" and went home \$28 richer!

After all had eaten, Kristin Gillum introduced a game for all – a good mixer and fun way to top off the event. Everyone, adults and youth, formed a large circle. The object of the game was to pass a small package and not be caught holding it when Chad Gillum (our whistler) hollered "STOP." After several minutes the last one standing without the package when "STOP" was called was guest Lauren Ping. She won \$20 in gift cards to Meier's. Hollie Kusssmaul was given the "first out" prize of a \$10 Meier gift card.

Our group is very grateful to our facilitator, Laura Sauerbeck, who obtained the park for us. A great time was had by all!

Kristin Gillum's story is really one of everyday bravery

On June 26, 2001, Kristin Gillum suddenly developed an excruciating headache.

"It felt like my head was on fire," she told fellow members of the Tri State Brain Aneurysm Support Group, during its September meeting. "It felt like there was a knife in my head."

Her husband, Robert, called 911. When they got to the hospital, doctors discovered that Kristin had blood on her brain. Further testing soon revealed the cause was an arterial venous malformation -- an abnormal growth in a portion of the vascular system supplying blood to her brain.

Because Kristin was 25 weeks pregnant at the time, she, Robert and their surgeon initially chose to try to stabilize the leak through an embolization and glue, using drugs to help her cope with the pain until her son, Joey, was born on Sept. 26.

But for Kristin the ordeal was far from over. Three months later surgeons used screws to install a halo around her head to

allow them to precisely locate radiation to shrink the malformation. "It was the worst pain," she said.

Kristin described living with headaches, feeling constantly tired, frequently repeating herself.

And she told her friends in the audience how tough it was when, in 2004, her surgeon discovered that another growth was forming, and she had to repeat the brutal radiation procedure.

"I've never gotten rid of my headaches," she said.

Many of us have come to know Kristin and Robert and their lovely children. And in part because so many of us struggle with headaches and pain and frustration, we have perhaps a special appreciation for what the Gillum family is achieving, doing day in and day out. And we'd sure like to thank them for sharing their story with us.

Speech disorders program draws big audience

By Bob White

Problems with speech and communication are an all too common consequence of brain aneurysms and the medical procedures required to treat them.

Hence, Krista Beyrer and Aimee Dietz found themselves before an appreciate audience on Oct. 7 when they discussed "acquired communication disorders" with members of the Tristate Brain Aneurysm Support Group.

Aimee focused on a type of communication disorder known as aphasia, which can affect not just speech, but also the ability to listen, read and write. Aphasia is not caused by muscle paralysis, low IQ or dementia, but can be triggered by damage to the brain (from an aneurysm or other vascular disorders involving the brain), tumors, viral or bacterial infections in the brain or degenerative neurological diseases.

Such speech problems can show up in a variety of ways, Aimee said. For example, sometimes patients understand the essence of an idea, but cannot express it fully. ("Coffee today Paul downtown," was the example she offered.

Some patients sound as if they're competent, but their speech is incomprehensible. ("Put the blufarb on the fibble.")

Some patients have limited understanding of language and severely constrained ability to speak.

Some patients with aphasia have normal or near normal understanding, but greater than normal difficulty in finding the words they want when they're trying to speak.

Aimee said there are a variety of strategies to help patients with aphasia. The strategies include a process known as circumlocution, in which one "talks through" a stumbling point until finding the word or phrase that



Speech experts Krista Beyrer, left, and Aimee Dietz, center, posed with Charlene Taylor following their presentation on communication disorders at the October meeting.

conveys the intended meaning. And some patients learn to communicate with the help of writing or drawing tools, communication books or electronic devices.

Krista's portion of the talk was devoted to a type of acquired speech disorder involving muscles and the physical aspects of speech. These types of problems are also common among those who have survived brain injuries.

As with aphasia, there are a variety of strategies for dealing with the motor skills involved with speech. Some, Krista said, are as simple as trying to speak loudly or slowly.

Krista has formed a social group for people with speech disorders, to give them an opportunity to practice successful strategies and socialize. She said this is a response to her observation that people with speech problems tend

to withdraw socially and -- even if they have been reasonably successful with speech therapy -- avoid situations where they might be required to speak in a group setting.

This group, called CHAT (Communication Helps Achievement Together), meets at Drake Center and at the UC Medical Center. For information contact Krista at 513.558.8522 or at krista.beyrer@uc.edu.

The University of Cincinnati is also conducting studies involving communications disorders. For one study researchers are recruiting caregivers of adults with communications disorders (due to stroke and brain injury) who attend local support groups. For another study researchers are seeking people with aphasia. For further information about either study please contact Aimee Dietz at 513.558.8551 or aimee.dietz@uc.edu.



Brain Aneurysms in the News

Cincinnati Enquirer, October 14, 2009

The remarkable comeback of Amber Gray

By Michael D. Clark, mclark@enquirer.com

It was a shocking image last August for anyone who ever saw the former Ohio Basketball Player of The Year glide effortlessly about the court.

Amber Gray led the Lakota West High School girls' team historic run to the 2008 state championship game.

But there she was, this nationally recruited athlete who went on to play last fall for the famed University of Tennessee "Lady Vols," slowly limping out of Cincinnati's Drake Center with a closed eyelid, double vision and her arm in sling. She had barely survived a stroke.

Her young and promising life had been threatened by a broken blood vessel in her brain a month earlier, forcing an emergency 12-hour operation and desperate measures to save her life.

And even when early physical therapy allowed the 19-year-old to walk gingerly away from her month-long stay at Drake, a return to normal life - much less college basketball - seemed a million steps beyond possibility.

But now there's a new image of Gray and it is miraculously merging with her past. To the surprise of her doctors, Gray is back on the court.

A recent afternoon found Gray at her old Butler County high school gym, dribbling a basketball and shooting.

Most of all she was smiling.

..."I've already shed tears of joy and tears of gratitude," she says with a satisfied grin after her quarter-speed shoot-around.

..."I've been blessed with being alive and having a second chance at life," says the deeply religious Gray.

Gray is a great-granddaughter of famed civil rights leader and former NAACP president Benjamin Hooks, who courageously marched with Dr. Martin Luther King Jr. during the often dangerous 1960s battles for racial equality.



University of Cincinnati News Record, October 14, 2009

UC receives \$8M for aneurysm research

By Sara Maratta, *The News Record*

University of Cincinnati researchers received \$8 million in stimulus funds to continue their study in identifying genes responsible for intracranial aneurysms.

The federal grant is a part of the 2009 American Recovery and Reinvestment Act.

"This grant is a big shot in the arm for our research," said Joseph Broderick, chairman of the UC neurology department and principal investigator for the study.

The grant supports the Familial Intracranial Aneurysm (FIA) II study spanning a two-year period.

"We're close to identifying the genes responsible for intracranial aneurysms," Broderick said. "But we still need to nail them down and the specific reason why they cause the formation of aneurysms."

UC is the coordinating center of the FIA studies. Phase I of the study was a five-year endeavor that involved participants from the U.S., New Zealand, Australia and Canada. The collaborative effort among 27 clinics investigated diverse populations.

"There were multiple results from FIA I that showed suggestive genes that could predispose or protect people from aneurysm," said Laura Sauerbeck, clinical manager of the study. "With this genetic research we need to replicate the findings of previous studies to make sure that the information is true, the money will help fund replication."

Phase II of the FIA study is structured to check for environmental and genetic factors that might be culpable of causing aneurysms.

Two genes in particular have been singled out for having a possible association with the aneurysms. The FIA II study attempts to replicate two different genes.

"If we can understand the genes and proteins that lead to intracranial aneurysms then we can help prevent them and understand why they happen," Broderick said.

The results of FIA II could lead to improvements in diagnosis, prevention overall screenings.