Aphasia in the News

ARC Cruise

23 members, friends and family of the Aphasia Recovery Connection just finished their 4-day cruise (March 4 though March 7) on Royal Caribbean. The cruise started in Miami, and the port of calls included Nassau, Coco Cay, and Key West.

Concerning the cruise, ARC co-founders David Dow and Christine Huggins (photo above) said:

"It was my first cruise ever," said Christine. "I am so thankful for meeting new people with aphasia, their

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Dear William,

This is Sharon Rennhack, the chief editor for the aphasiatoolbox newsletter.

Aphasiatoolbox has received questions from clients about the use of the drug Enbrel (trade name Enbrel) for stroke and aphasia.

Additionally, we have two clients who have scheduled their visits with Dr. Edward Tobinick and colleagues for evaluation and injections. We will follow their stories, and report on their recovery in the next edition.

And, you may have noticed that we are revamping the aphasiatoolbox newsletter. We want to make this newsletter the voice for the aphasia community - SLPs AND People with Aphasia. Contact me, and let us know what your interests are/what you want to read.

Sincerely,

Sharon Rennhack
Chief Editor
Aphasiatoolbox

March 26, 2013
families and friends, and the professionals too!"

"I was so happy for the friendly faces," said David. "Christine and I will be planning the next cruise."

Some of the "cruise happenings":

Dr. John Schultz announced his retirement from the Duke University School of Medicine, Dept of Anesthesiology. He plans to move to Las Vegas.

The 'ARC cruisers" included Lauren Cook and Marianne Conrad, (photo below) two future SLPs, now studying at the University of Toledo. They have been interning at the DaZy Aphasia Centre in Toledo, with Melodie Dregansky.

We also witnessed a romantic proposal and engagement on deck; for the sake of privacy, we can't give any more details!

We all agreed on some of our favorite things: the excursions, the food, especially the desserts, the entertainment, sun, sand and water, and for some, pure relaxation - no telephone, no cell phone and no computer!.

A good time for all!

IAM Spanish Therapy

THE INTERNATIONAL APHASIA MOVEMENT is offering a free Spanish Aphasia Therapy program.

Meetings and therapy will take place at:
The Institute for Music and

New Tools on aphasiatoolbox

These exercises have just been added to Aphasia Sight Reader:

a. Module- Cognitive Skill Support
   Exercises - Verbal Working Memory: Sentences 1 or scaffolded.

b. Module- Long Term Care
   Exercise - Assemble Sentences

c. Module- Pronouns
   Exercises -
   Subjective to Objective Pronouns
   Objective to Subjective Pronouns

d. Module - Verbing
   Exercise - Canonicalize Sentences

Upcoming aphasiatoolbox presentations

Bill Connors will be presenting on Aphasia-Apraxia Therapy: Exploiting Neuroplasticity, at these locations:

March, 27-30, 2013
Consumer and SLP Consultations, Dallas, TX
Individual consultations and social networking meetings.

April, 27, 2013, Tampa, FL

May 18, 2013, Bismarck, ND

May 23-26, 2013, Marco Island, FL - Presenting at the Florida Speech Hearing Association Conference

These presentations will include aphasiatoolbox clients and staff members.

For more information, please see our EVENTS page; if you are interested in sponsoring a workshop in your area, contact Bill Connors at Bill@aphasiatoolbox.com or 724-494-2534.
Neurologic Function (IMNF)
612 Allerton Avenue, Bronx,
New York City

Meeting dates:
Every Tuesday and Thursday
Meeting times: 5 pm - 7 pm

Call to Register:
Nicole Riviello at 212-844-0565 or check the website
- aphasiamovement@aol.com

ARC Aphasia Conference in June

The Aphasia Recovery Connection is offering an Aphasia Conference and Jam in June.

Sponsors of this event include the Las Vegas Affiliate of the American Stroke Association and St. Rose Dominican Hospitals.

This event is FREE!

Here is the schedule:

Sunday, June 23: Fun and social / aphasia movies / games

Monday, June 24th: Fun and social / Viva Las Vegas Day

Tuesday, June 25th: The fun continues. Then, the evening starts with a pre-conference kickoff event with our keynote speaker (a renowned therapist to be announced!)

Wednesday, June 26th & Thursday, June 27: Aphasia Conference Days (2)

Friday, June 28th: Stroke Conference Day

The registration forms will be coming out by the end of March.

For information, contact Carol Dow-Richards.

Love After a Stroke

Perispinal Etanercept for Stroke and Aphasia

The man behind Perispinal Etanercept is Dr. Edward Tobinick, the founder and director of the Institute for Neurological Research, a private medical group. He is board-certified, and is an assistant clinical professor of medicine at the UCLA School of Medicine.

Tobinick has patented his use of Etanercept as TransBarrier™ drug delivery of Etanercept, including U.S. patents 7214658, 7629311, 8119127, and 8236306.

The drug Etanercept, known by its brand name Enbrel, has been proven effective in reducing Tumor Necrosis Factor or TNF; this is the chemical process that causes the inflammatory response in the body. The drug has Food and Drug Administration approval for treating rheumatoid arthritis and psoriasis.

As an Anti-TNF treatment, this drug reduces inflammation following a stroke. Tobinick injects the medicine at the back of the neck, then dips the patient backward at a 45-degree angle.

In about five minutes, the drug enters the brain and spinal area through the cerebrospinal venous system and and the cerebrospinal fluid; reportedly, the injection instantly fights the inflammation.

The institute's website contains video-taped stories of patients discussing their personal improvements after this treatment. While these are personal accounts of progress, not research based studies, many of them demonstrate remarkable, positive changes.

Because this treatment is considered to be an "off-label" use of etanercept, it is is not FDA-approved. Treatment is not covered by Medicare or most insurance plans.

Two specialists from Oklahoma City, Oklahoma, Dr. David Gordon and Dr. Charles Morgan, have expressed their skepticism of Perispinal Etanercept. Dr. David Gordon is the neurology chairman at the University of Oklahoma College of Medicine. Dr. Charles Morgan is the medical director for the Integris stroke center.

Dr. Gordon said that Tobinick should have relied on extensive, controlled clinical studies to ensure the treatment is safe and effective. Dr. Morgan says: "I can tell you this stuff is nonsense. "I would strongly advise patients to not do that," he said. "You may get by with it. It may damage you. No way is it going to help." He added: "I'm extraordinarily skeptical of this medication for this use."

A peer-reviewed study published in December 2012 said:

"Tobinick's Institute of Neurological Recovery gave Etanercept injections from November 2010 to July 2012 to 617 stroke patients and 12 patients who had suffered a traumatic brain injury. Of the total studied, more than 80 percent saw improvements in their ability to walk;
When Megan Nosol was a graduate student in Speech-Language Pathology at the University of North Carolina in Chapel Hill, she wrote and self-published a book for children and their families about Aphasia and stroke, titled *Love After a Stroke*.

Megan's book is viewable on Youtube and can be purchased through Lulu Marketplace. All royalty proceeds go to the National Aphasia Association.

Megan is currently a Graduate Clinician (Head and Neck Cancer) at UNC Health Care, Raleigh-Durham, NC.

Gabby Giffords - Profile in Courage

Former Arizona Congresswoman Gabrielle Giffords will receive the John F. Kennedy Profile in Courage Award for her efforts to curb gun violence.

Giffords is to receive the award, given annually by the John F. Kennedy Library Foundation, in recognition of the "political, personal, and physical courage she has demonstrated in her fearless public advocacy for policy reforms . . . Instead of retreating following the tragic shooting that ended her Congressional career, she has recommitted herself to fighting for a more peaceful society free from hate and violence. She is a true Profile in Courage," Caroline Kennedy said in a statement released by the foundation.

Giffords survived a gunshot wound to the head two years ago. She spent months in a rehabilitation facility in Houston, Texas, where she more than 80 percent had less spasticity; and more than 85 percent exhibited improved motor function. Improvements also were recorded in many patients' range of motion, pain and cognition, as well as their ability to speak, see, swallow, concentrate and maintain bowel control."

It appears that some people are satisfied after a single dose. Tobinick recommends a second injection after one month if patients want additional improvement; about a quarter of his patients choose the second shot.

Dr. Tobinick said that the first patients treated in November 2010 continue to enjoy improved mobility and cognition.

A list of scientific publications regarding this procedure is available here.

References for this article:


Information:

Institute of Neurological Recovery

Locations:

2300 Glades Road, Suite 305E, Boca Raton, FL 33431 (561) 353-9707

361 Hospital Road, Suite 428, Newport Beach, CA 92663 (310) 824-6199

100 UCLA Medical Plaza, Suites 205-210, Los Angeles, CA 90095 (310) 824-6199

URL:

http://www.instituteofneurologicalrecovery.com/

http://www.strokebreakthrough.com/

http://www.tnfmedicine.com/tnf/

Young adult stroke is on the rise

One out of seven patients with stroke between the ages of 16 and 50 was misdiagnosed according to a 2011 study conducted by the department of neurology and stroke program at Wayne State University/Detroit Medical Center.

According to program director and study co-author Seemant Chaturvedi, M.D., professor of neurology and Fellow of both the American Academy of Neurology (AAN) and the American Heart Association,

One out of seven is not a trivial number when you
recovered some of her ability to speak, walk, read and write.

Despite her aphasia, Gabby is now appearing in public.

consider that more than 50,000 young people have a stroke each year. Early use of magnetic resonance imaging (MRI) can improve diagnostic accuracy in young adults with stroke, as can having a neurologist see the patient in the emergency department.

Group of the Month

The StrokeFoundation.com is dedicated to providing the latest news and comprehensive information about Stroke and Aphasia.

The website includes sections on Aphasia, Attitudes, Emotions, Food and Nutrition, and much more.

twitter: @strokenews
Website: www.thestrokefoundation.com

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Many well-known people have had strokes at a relatively young age: actor Kevin Sorbo, actress Sharon Stone; Sen. Mark Kirk (R-Ill.); Beau Biden, son of U.S. Vice President Joseph Biden; Tedy Bruschi, former linebacker for the New England Patriots, and singer/songwriter Bret Michaels; to name a few.

Stroke symptoms such as dizziness or headache can be confusing-mimicking signs of other conditions, including brain tumor, multiple sclerosis, spinal cord injury, or serious infection. Stroke can also masquerade as vertigo, alcohol intoxication, inner ear disorder, or migraine headache.
