



The National Aphasia Association
 a•pha•sia (uh-fay'-zhuh) n. An impairment of the ability to use or comprehend words, usually acquired as a result of a stroke or other brain injury.



NEWSLETTER

May 2009

350 Seventh Avenue, Suite 902
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MESSAGE FROM THE PRESIDENT OF THE NAA



Happy May! We are so excited about the upcoming production of the play *Night Sky*! The play will run from May 22-June 20 at the Baruch Performing Arts Center with a special Benefit Performance on June 4th. We will be presenting our 2009 Aphasia Advocacy Award to John Liechty at the benefit along with a star studded reception.

Dan and I attended a reading of *Night Sky*, the play which will be the theme of our Benefit this year. It was so compelling, and well acted, that we both cried and laughed. It's much more than an inspiring story of triumph, however - it really

is about communication and family dynamics when under stress, and about hope.

Please make sure all your friends hear about it and encourage them to see it - on June 4 if they can! You can promise them an evening of great theater and superb acting!

June is National Aphasia Awareness Month and we have a new theme and poster for 2009. Contact the NAA for your packet and be sure to let us know about the events you are planning in your area. Get your local representatives to proclaim June Aphasia Awareness Month in your city/state.

As we continue to work towards achieving our mission and goals your support is invaluable. We thank you for your generosity and efforts. We look forward to hearing from you and increasing awareness of aphasia together!

Best regards,

Barbara C. Martin

IN THIS ISSUE:

WE GOT MAIL	2
Paul Dane Walking Marathon	3
NAA Group of the Month	5
Phillip Dann Back to Singing	7
Blair Justice Speech	10
NEWS & NOTES	16

We Got Mail!

Here is an e mail we received
from *Judy Dane* whose husband,
Paul, has aphasia:

I thought I'd send this article to you about my husband and I and a few therapists that have joined us in the fight to end stroke. Paul and I have been to several speaking out conferences and he also has spoken or should I say used his computer to introduce some guests at ASHA. He and I were the volunteers at your booth in Boston for the ASHA conference.

Paul had his stroke 7 years ago while we were living overseas. Needless to say Paul's stroke caused him to have Aphasia. When the American Stroke Association sent an email out early this year about Train to End Stroke, I casually said to Paul, what'd you think? He said in his limited speech lets go for it. Our team decided to give us the name THE GREAT DANES! The team consists of Liz Hoover who is a speech therapist from BU works at the Aphasia Community Resource Center at BU where Paul attends several groups each week working with Liz and her students. Laura Glufing-Tham is a speech therapist at Emerson College who Paul and I met at our first Speaking Out Conference in Florida and worked again with Laura organizing the conference here in Boston. Anne McCarthy Jacobson is the third member of our team. Anne is a physical therapist at MGH IHP and Paul has worked with her and her graduate students. Working with adults with Aphasia is a great experience for the students and Paul wouldn't be able to do this walk without the help of Anne and her group.

I am personally very proud of Paul for taking on this challenge and honored to be part of such a great team. I do hope that you will consider using this article in your June issue since it is Aphasia Awareness Month. The marathon is in Burlington, Vermont on May 24th, Memorial day weekend.

Thank you,

Judy Dane

Hampstead Stroke Victim Trains for Walking Marathon

By Margo Sullivan

margosullivan@eagletribune.com



HAMPSTEAD — At 62, **Paul Dane** is taking a giant step toward recovering from a stroke he suffered seven years ago. Dane is training for the Vermont City Marathon, scheduled for May 24, in Burlington. He will walk two to three miles of the 26.2-mile course to benefit the American Stroke Association.

The rest of his team, wife, Judy, and three of his therapists, will walk the other legs of the race, but they want him to cross the finish line. That will be a giant step for the former aeronautical engineer, who was initially paralyzed on his right side and unable to walk at all, his wife said.

To raise money for the walk, the Danes raffled off gift baskets and held yard sales. They hope to raise \$5,800. Their team is called the Great Danes. Dane started the training slowly by walking around the neighborhood, but he has been building up his strength and stamina, his wife said. **"Paul walks right now up to one and a half miles in 45 minutes,"** Judy Dane said. **"When he first started, he couldn't keep up the pace."**

The team has to finish the marathon in six hours, she said. Dane, who has set up a computer show about the team and the marathon, joked they have assigned their youngest marathoner to the toughest part of the course. His speech therapists, Liz Hoover of Boston University and Laura Glufing-Tham of Emerson College, and his physical therapist, Anne McCarthy-Jacobson of Massachusetts General Hospital, also are on the team. The course starts downtown and moves into neighborhoods, then passes through woods and up hills. Dane is still battling aphasia, a communications disorder brought on by stroke. His intelligence was not affected, but he has difficulty speaking.

Dane was on a flight to Norway when he was stricken. His wife, who was on the plane with him, recognized the symptoms and called for a doctor. The airline landed in Milan, Italy, so Dane could be seen at a hospital, but he suffered complications. Ultimately, he underwent surgery in Geneva, Switzerland, before returning to the United States for extensive therapy.

"Paul was determined to walk again," his wife said.



NAA Group of the Month



Extended Day Aphasia Program at the Ladge Speech and Hearing Center at Long Island University, C.W. Post

For the person with aphasia, communication barriers presented by language impairment may be the most challenging than impairment resulting from stroke. In order to address the communication needs of individuals with aphasia, aphasia remediation has a dual focus: first, to develop functional communication techniques that will maximize the successful exchange of ideas; second, to minimize, as far as possible, the degree to which aphasia affects the person's ability to participate in activities he/she enjoys.

University clinics, like the Ladge Speech and Hearing Center, are often the places where long-term, low cost therapeutic services can be provided. We have expanded the individual and group speech-language therapy services we provide people with aphasia by establishing an extended day program. This program is a place where people with aphasia and their families can engage in a variety of social and therapeutic activities with the aim of decreasing isolation, aiding adjustment to disability, improving self esteem and reducing dependency on a single caregiver. Most of these activities are conducted by graduate student interns in speech-language pathology under the supervision of NYS licensed speech-language pathologists.

(continued on page 5)

NAA Group of the Month



LADGE SPEECH AND HEARING CENTER



Program Schedule:

- | | |
|---------------|--|
| 10:00 - 10:30 | Meet and Greet : General Conversation |
| 10:30 - 11:00 | Music and Movement |
| 11:00 - 12:00 | Choice of Current Events Group or Living with Aphasia Support Group |
| 12:00 - 1:00 | LUNCH |
| 1:00 - 2:00 | Social Activities: Non-Linguistic, Educational and Social Activities (art, music, poker, Wii, crossword puzzles) or Special Presentations |



NAA Group of the Month

(continued from page 5)

The power of the socialization component of this program is palpable. As the clients come to know each other, they grow more secure and willing to communicate with each other and the staff. During the meet and greet sessions, a conversational din fills the room.

Clients, who were first passive and somewhat inattentive, have become animated; their personalities becoming more apparent as they connect with others and participate in enjoyable activities of their choosing. The following are statements of people with aphasia and their spouses who participated in the six week program last summer. One spouse said of her husband with aphasia, "I really didn't think I would see much change in just six weeks, but he's so much more like his "old" self. He is expressing more spontaneously. He is making jokes and commenting to strangers which he never did." One of the clients with aphasia said, "This program is 110%! I learned computers. I really, really, appreciate it." A third spouse reported, "Even our friends have commented that Bill is talking more. He is saying three and four syllable words more clearly and attempting longer words that he wouldn't have even tried before." Another client likes the program because, "I am always busy."

We strive to make this program a place where the affects of the aphasia are minimized; a place where people with aphasia can effectively communicate with others; a place where people with aphasia can make new friends.

This program serves people with aphasia whose comprehension is good enough to follow a conversation and sustain four hours of interaction. Healthcare aids or other caregivers are welcome.

The summer program will meet on Mondays and Wednesdays from 10AM to 2PM for eight weeks in July and August. During the fall and spring semesters the program meets Mondays from 10 AM to 2 PM for 11 weeks. For more information contact Dr. Dianne Slavin at dslavin@liu.edu or Dr. Joyce Rubenstein at jrubenst@liu.edu or call 516-299-2437.

We are pleased to print the text of a talk given by Phillip Dann, a person with aphasia, at the Association Internationale Aphasie Conference in Estonia in October 2008. Phillip was an attendee at our 2008 Speaking Out! Conference.



BACK TO SINGING

Phillip Dann

**Association Internationale Aphasie
October 24, Tallinn, Estonia**

I was quite good at singing. But after my stroke fifteen years' ago I am aphasic. It's my journey back to singing with aphasia.

I was born in North Wales, in Bangor. My mother of course sang to me when I was a toddler. At school we sang nursery rhymes, folk songs and hymns; and some of the time we sang in Welsh.

In primary school I joined the choir. The headmaster was very strict, but he was also a composer, a pianist and an organ player. He played in the service at church as well. In my time the choir recorded two discs: one in Welsh and one in English. I started the piano and, later on, the viola.

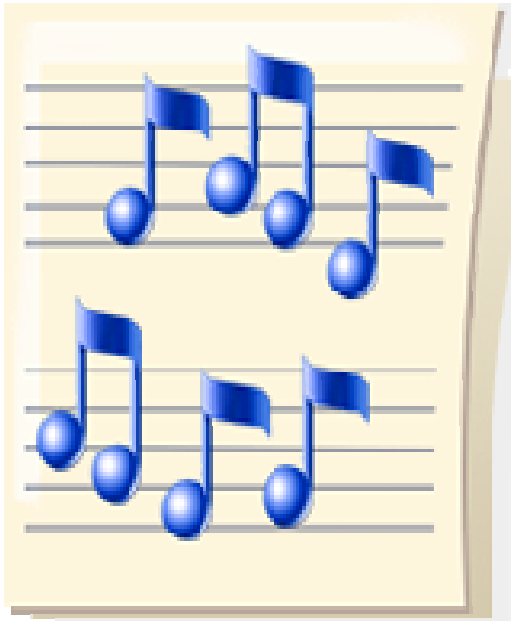
When I was thirteen we moved to Manchester. Now, the population in Bangor was roughly 18,000 people. Manchester was roughly 750,000 people. As a teenager it was exciting: football, the theatre, cricket and concerts. My hero as a conductor was Sir John Barbirolli. I went to many concerts at the Free Trade Hall.

Before, in Bangor, I sang with a treble voice; but roughly the same time we moved, I dropped down to a bass voice. I went to Manchester Grammar School and there the music was excellent. I joined orchestra and choir.

We sang the complete works by Handel (The Messiah), Haydn (The Creation), Elgar (The Dream of Gerontius), Stravinsky (The Symphony of Psalms), etc. Also, we tried Barber Shop, jazz, musicals and hymns.

(continued on page 8)

(continued from page 7)



Later on, I went to the junior Royal Manchester College of Music, on Saturday. I was quite good at the piano and lousy at the viola. I was thinking about going on to study music at some university but I said to myself, I'm pretty good at music, but not that good. I chose law and the university accepted me.

At Cambridge I studied hard but not too hard! My college was Trinity Hall. I joined the chapel choir and it was a quite good orchestra. The Cambridge Choir auditioned me. The first time I failed but the second time I got in! Two concerts in particular were breathtaking: Mahler's Symphony Number 8 at Ely Cathedral and the Royal Albert Hall, London.

After Cambridge I went to Paris researching comparative law, and then back to Cambridge studying international law. The first proper job was at the University of London lecturing in law. Then, I went to the Bar and joined Lamb Building in London. Afterwards, I moved to Inmarsat, the international agency specializing in sea and aircraft satellite telecommunications. My final full-time job was at Bird & Bird, a solicitors' practice, specializing in telecommunications law. And I lectured in space law. All the time, I sang at home, in church and, sometimes, amateur concerts.

Then, aged forty, I had a stroke in the night when I was asleep. I was rushed to the Whittington Hospital, then the National Hospital and finally the "rehab" unit at East Finchley: in total it was four months. At the start I spoke two words only: "no" and "toilet"! Singing was beyond my comprehension.

Some of my friends bought a little television beside my bed at hospital. It was kind but I rarely watched it: it was too difficult. I didn't listen to the radio. But I did go to the speech and language lessons every day and I continued the lessons as an out-patient.

Now, singing and speech are two different things but closely related. Relearning my speech was one factor and I thank the speech and language therapists. Of course, they finished with me two years' after my stroke but my speech was going on improving and it's still improving.

(continued on page 9)

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My singing – again after my stroke – was a problem. I didn't sing at home. What was the reason for that? I didn't have confidence to sing. Also my speech was not good. Finally, listening to music was fine but it was difficult to listen to a long pieces.

But I plucked up courage and, four years' ago, I joined two local choirs. The first was Cholmeley Music Society. Cholmeley was a real man, he was born in the 16th century and he founded Highgate School. We sing the great pieces but we have no auditions. You come along and you paid the subscription. That's all.

And my speech is not a problem. Sometimes it's quite good and other times it's pretty bad but they understand. Every term we have a concert: the December and April concerts have a big piece or pieces, like Bach's Mass or Brahms' German Requiem. In the summer we will sing party pieces, light pieces.

The second choir is the church choir, St. Michael's, Highgate. Samuel Coleridge, the poet, is buried in the church. He lived opposite St. Michael and much later on J B Priestly, the novelist and playwright, lived in the same house. Today, four doors up, lives George Michael, the pop star. But I am straying off my subject.

We sing every week at Sunday morning service and once a month in the evening. The British composers love to write church music but we have also Palestrina, Bach, Mozart, Schubert and Fauré. Or Medieval chants.

Again, our Music Director is sympathy about my speech. And, it's very much now than before. I remember now the words in the Holy Communion service. But in the Psalms – so many Psalms! – it's still difficult mouthing the words.

I am singing much better: the large throat, the control in the stomach, stand up posture, etc. And the new Assistant Organist is also a singing teacher and very helpful. Of course I am middle-aged now and the control is a little bit weak. Also I'm interested about my drooping right cheek: may be it's a specific problem or may be it's nothing. I will find out and talk to a speech therapy.

I will not sing now - but may be in a bar I might sing there!

BACK TO SINGING

Phillip Dann



Blair Justice, an NAA Board member, and his wife, Rita, joined NAA Executive Director, Ellayne Ganzfried, for a presentation at the Texas Speech-Language-Hearing Association's 53rd Annual Convention in Austin in April.

Blair wrote and recited the following speech which was so inspiring that many requested the text:



“I feel trapped by the
voices I can't express.

I feel the words
that go unexplained.”

“Presence is a noun, not a verb,
“it is a state of being.”

These are from a poem by Walt Whitman.
Before I went back to Whitman's poetry,

I had little understand why people
who know me well
can't understand me when
I say I don't know what they mean.

Or they ask me questions I can't answer.

Or they tell me two things I should do together,
which one is first, which is second.

Or they say everyone gets to an age
what words they said earlier.

Or what if 8 to 10 words I have on my computer --
documents, email, internet, Goggle –



I should not know which I should use
to find what I am looking for.

Or which patient at M.D. Anderson
wanted which item—lotion, deodorant or toothpaste.

Or I sat next to a person I know from the recent past,
but I can't remember.

(continued on page 11)

(continued from page 10)

When I tell my cousin and her husband,
I can't remember faces or name any more,
they tell me anyone our age can't remember much.

When I tell my wife, Rita, I can't button my shirt.
or I can't get a new bottle of wine to open,
she immediately takes over.

When I stop to consider what my two dogs can teach me –
“presence is a noun, not doing.”

So what some people recognize me for who I am,
So Rita humors me about not driving my car our out of town,

I stop to consider that presence is a noun, not a verb,
In 2010, the U.S. Government will publish a “Healthy People” objectives.
As you have seen, I suffered a stroke on September 11, 2004.
By the time I had a brain attack, which was caused by the stroke, I had largely
finished a book that I wrote, called *Raising Lazarus: The Science of Awakening
the Soul*.

The U.S. Surgeon General and the Public Health Service have declared that well-being
is the proper measure of health. What is well-being?

It is a sense that life is good despite an adversity.
With the help of my wife, Dr. Rita Justice, and my co-author, Pittman
McGehee, a Jungian therapist, we have sent the book off for publication during
the spring of 2009.

I am an Emeritus Professor of Neuropsychology at the University of Texas School of
Public Health. I was the associate dean for Academic Affairs
of the school for eight years. I have been a volunteer for 10 years at M.D.
Anderson Cancer Center, treating patients on two floors, 9th and 11th.

Ten years ago, I did a face-to-face interviews with women who had treatment for
breast cancer. Two years later, I contacted the women and asked this question:

“In general, do you consider yourself a healthy person, very healthy person, a sick
person or very sick person.”

All still experienced pain or several stages of disease. Twelve of the 13 women
interviewed said: “I am a healthy person.” Many were still experiencing pain or
were in active stages of disease.

(continued on page 12)



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I was fascinated by the finding – which are consistent with many adult health surveys among thousands of Americans. Many with serious diseases or other disabilities answer: **“I am a healthy person.”**

I wrote about what I learned from these women and other researchers in the field of subjective health in my 1998 book, ***A Different Kind of Health: Finding Well-Being Despite Illness.***

They do so on this basis: They recognized that a person has more aspects than the physical. We have a relationship part to us, we have an achieving part, and we have an emotional and mental part, we have a spiritual part, and we have a core part as a person.

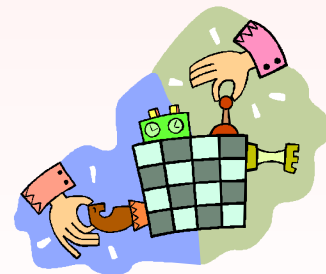
Being sick or in pain in the physical part doesn't mean we can't be healthy in those parts. A sense of inner health – also a subjective health or self-perceived health – shift their identity as a person from the physical to the healthy nonphysical parts.

How do people with disease or disability gain a sense of well-being? They do so on this basis: They recognize that being a person has more aspects than the physical. We have a relationship part to us, we have an achieving part, we have an emotional and mental part, we have a spiritual part, and we have a core part as a person.

Being sick or in pain in this physical part doesn't mean we can be healthy in those other parts and at our core. Those who have pathology but a sense of inner health – also called a subjective health or self-perceived health – shift their identity as a person from the physical to the healthy nonphysical parts.

There are two common pathways:

- 1. Perceiving some value or benefit in one's illness experience, bad as it is.**
- 2. Finding some activity, interest or experience that is so engrossing and engaging that one gets outside the self and loses a pre-occupation with pain and suffering.**



(continued on page 13)

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What are examples of these experiences:

1. Becoming more patient, compassionate, understanding – improving as a person.
2. We cognizing that having a heart attack, getting cancer or having a stroke or related experience was a “wake-up call,” alerting us to change us our way of living and thinking.
3. Re-ordering our priorities as a result of getting sick or have a stroke or having a chronic pain – deciding that what’s important in life are a relationship or appreciation of nature or service to other, all “intangible” compared to materialistic symbols of success – power, money, big homes, fast cars, “excitement.”

What are examples of getting outside ourselves?

1. Discovering a talent or interest you didn’t know you had and becoming so absorbed in it that you lose yourself in it and forget about the pain or disease.
2. Becoming dedicated to serving others and finding that in giving, one receives.
3. Taking delight in the ordinary by learning to literally “stop and smell the roses.”
4. Letting go of old resentments and angers by forgiving. Research show that holding onto resentments and angers is very stressful. When they are letting go, much relief occurs.
5. Discovering or rediscovering that attending church and becoming a part of a part of a religious group enhances strength and relieves suffering.

When we do sense or part of all this, we then are following in Fordyce’s Law.

Dr. Willard Fordyce of the University of Washington Medical School and father of pain research in the United States established what has become known as “Fordyce’s Law. In plain English, it says:

“People suffer less when they find something better to do.”

Rita will talk to you now about something better we have found to do.



NIGHT SKY
A PLAY
BY
SUSAN
YANKOWITZ
DIRECTED
BY
DANIELLA
TOPOL

Night Sky

Performing at Baruch's Rose
Nagelberg Theater

Baruch Performing Arts Center

55 Lexington Avenue
Entrance on E. 25th Street
between Lexington and 3rd Aves;
NY, New York 10010

Previews Begin Friday, May 22nd

**Regular Performances begin
Friday, June 5th and run to June 20th**
Tuesdays through Fridays at 8pm
Saturdays at 3pm & 8pm
Sundays at 3pm

(No 3pm show on May 23rd, No performance June 3rd,
Added performance Monday, June 1st at 8pm)

**June 4th at 7pm – National Aphasia Association
Benefit Performance and Gala Reception**

(Ticket Information on page 15)

NIGHT SKY

NIGHT SKY
A PLAY
BY
SUSAN
YANKOWITZ
DIRECTED
BY
DANIELLA
TOPOL

The National Aphasia Association (NAA) is a nonprofit organization that promotes public education, research, rehabilitation and support services to assist people with aphasia and their families.

www.aphasia.org

NIGHT SKY explores what the great physicist Stephen Hawking has called the two remaining mysteries — the brain and the cosmos. The play looks at what happens to a brilliant, articulate astronomer, her family and career when she is struck by a car and loses her ability to speak, a condition known as "aphasia." What emerges from her mouth is a hodgepodge of disconnected words alternately poetic, funny, confusing and profound. Anna, her loved ones and colleagues, face uncommon challenges of mind and spirit as they must fight as they learn new ways to communicate, and what it really means to listen.

To purchase tickets go to
www.nightskytheplay.com

Group Rates are available for groups of 10 or more!

\$40 for adults/\$25 for students

contact groupsales@lavieproductions.com

for more information or to make reservations



All Preview Tickets

Friday, May 22nd – Monday June 1st

Only \$45!

Same Day Rush – Cash Only at Box Office

Only \$25!

Regular Price Tickets

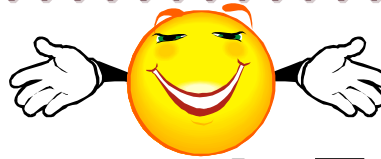
Starting Friday, June 5th

\$45 & \$65

Same Day Rush – Cash Only at Box Office

Only \$25!

NEWS AND NOTES



WELCOME

The NAA welcomes the following new State Representatives:

Cristi Chauncey (SLP) - GA

Terria Hampton (SLP) - SC

Fabi Hirsch (SLP) - AZ

Gloria Olness (SLP) - TX

Carol Page (SLP) - SC

Jennifer Stein (Recreational Therapist) - SC



June is National Aphasia Awareness Month

Posters and Packets are now available!!

Get your city and/or state to proclaim June as National Aphasia Awareness Month. Sample proclamations are on our website: www.aphasia.org

Hope you are planning your Aphasia Awareness Month Activities!

Contact us at naa@aphasia.org or (800) 922-4622

NAA Group of the Month!!

Sign up to be the NAA Group of the Month! Spotlight your group and activities - let everyone know what makes your group unique and special. Pick any month between August - December 2009

Contact Ellayne Ganzfried at Ganzfried@aphasia.org or

call (800) 922-4622 to reserve your place!



We want to feature information about
**ALL Aphasia Groups, Centers, events and
personal experiences**

so please email us at naa@aphasia.org with your
announcement or an article of interest about
your program.

You can also visit our website www.aphasia.org for all current listings.

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