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USSAAC
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SpeakUP

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United States Society for Augmentative & Alternative Communication



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to Attend
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**Priorities
& New
Administration**

**Thoughts from
AAC User**
Rick Hohn

USSAAC
Remembers
Member
June Downing

BRAIN-COMPUTER INTERFACE:
LOCKED-IN
& Reaching New Heights

Gregory Bieker Portland, Oregon

Locked-in and Reaching New Heights

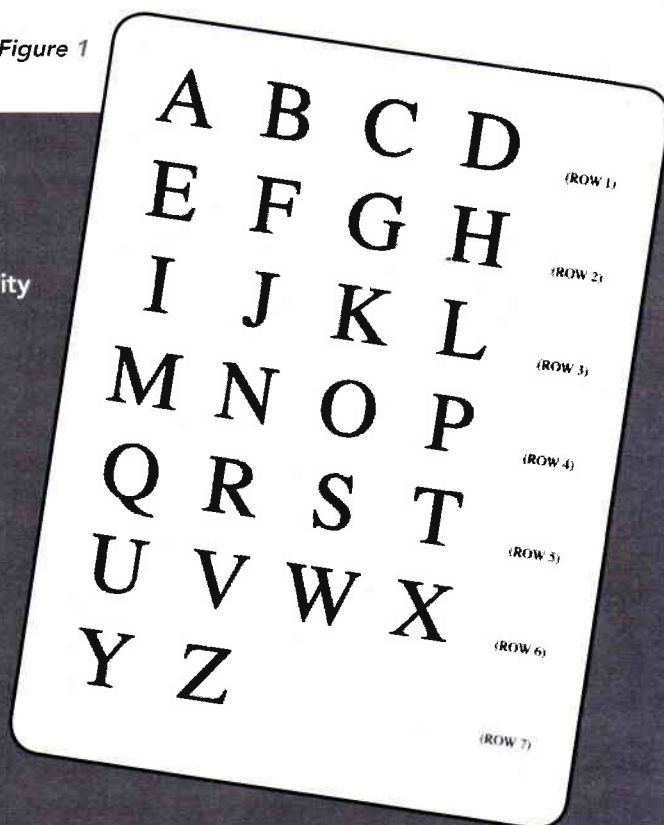
GREGORY BIEKER Portland, Oregon

Glory Noethe, MPH and Melanie Fried-Oken, Ph.D. Oregon Health & Science University Portland, Oregon

introduction

My name is Greg, and I had a brainstem stroke 16 years ago. As a result, I have locked-in syndrome (LIS). If you did not know me, you would not guess that my cognition is intact. I am totally paralyzed but I have minimal head movement. I do have the ability to look up for "yes" and down for "no." To communicate, I use eye gaze with an alphabet chart. The chart is broken down into seven rows; the first six rows have four letters each and the seventh has the last two letters of the alphabet (see Figure 1). My communication partner starts with row 1 (e.g., says "1, 2, 3, 4") until I gaze up, which means, "yes, we're on the right row." Next, my communication partner will call out the letters of the alphabet that correspond to the chosen row (e.g., if row 3 is chosen then he will say, "I, J, K, L"). When the correct letter has been called out I will gaze up. This is how I construct full words, sentences, paragraphs, and pages. Just to give you an idea, when I'm communicating with someone very proficient, it takes me about 25 minutes to write a paragraph.

Figure 1



my history

I grew up with my mom, stepdad, sister, and three stepbrothers. I graduated from high school in 1986. During my high school years, I was active in wrestling, football, and basketball. In 1985, I went to the State Championships for wrestling and placed 3rd. The picture of me with my trophy is still hanging up in my high school, where my nephew will be going to school next year. In football, I played the position of running back. Basketball was always my favorite sport and still is (Go Lakers!). I enjoyed playing the game. My favorite position was guard, because I was good at it.

After high school, I joined the Army where I spent the next three years living in Germany as a Communications Specialist. I was fortunate to be enlisted during peacetime. I was also fortunate enough to be in Berlin when the wall came tumbling down. I brought a rock from the Berlin wall home to my mom, which she still has. While living in Europe, I was able to do some traveling. The Netherlands was my favorite place because of the breathtaking scenery. I will never forget my time there because of the beauty.

the accident

After leaving the Army, I used my G.I. Bill to enroll in community college. My focus was business management. After completing my first year of college, I was in a devastating car accident that sent me to the hospital in need of surgery. After my surgery, I had multiple strokes and ended up in a coma. When I woke up, I was completely paralyzed. I was in a skilled nursing facility for the next three years. After three years, I was able to move back to my parents' house. This was nice because I could interact with my family on a daily basis, which meant a lot to me.

Communication post-accident
During my time at the skilled nursing facility, I was introduced to both low-tech and high-tech augmentative and alternative communication (AAC) devices. I learned how to use a chart compiled of letters to help me communicate. I have been using the same chart reliably for the last 16 years. In the beginning, I also used the KENX system, which was a head switch attached to a computer for row-column scan typing. The system had voice output, which I could take or leave. After a short time, that system became too slow for me and using the chart became the fastest way for me to communicate. Talking for me is spontaneous and the KENX system did not allow for spontaneity. I think the eye chart is much more convenient because I don't have to stay stationary attending to a computer. To date, the chart is still the fastest way for me to communicate for two reasons. First, my communication partner is faster than a device at getting my message out. Second, the set up time for most devices

is strenuously
time consuming

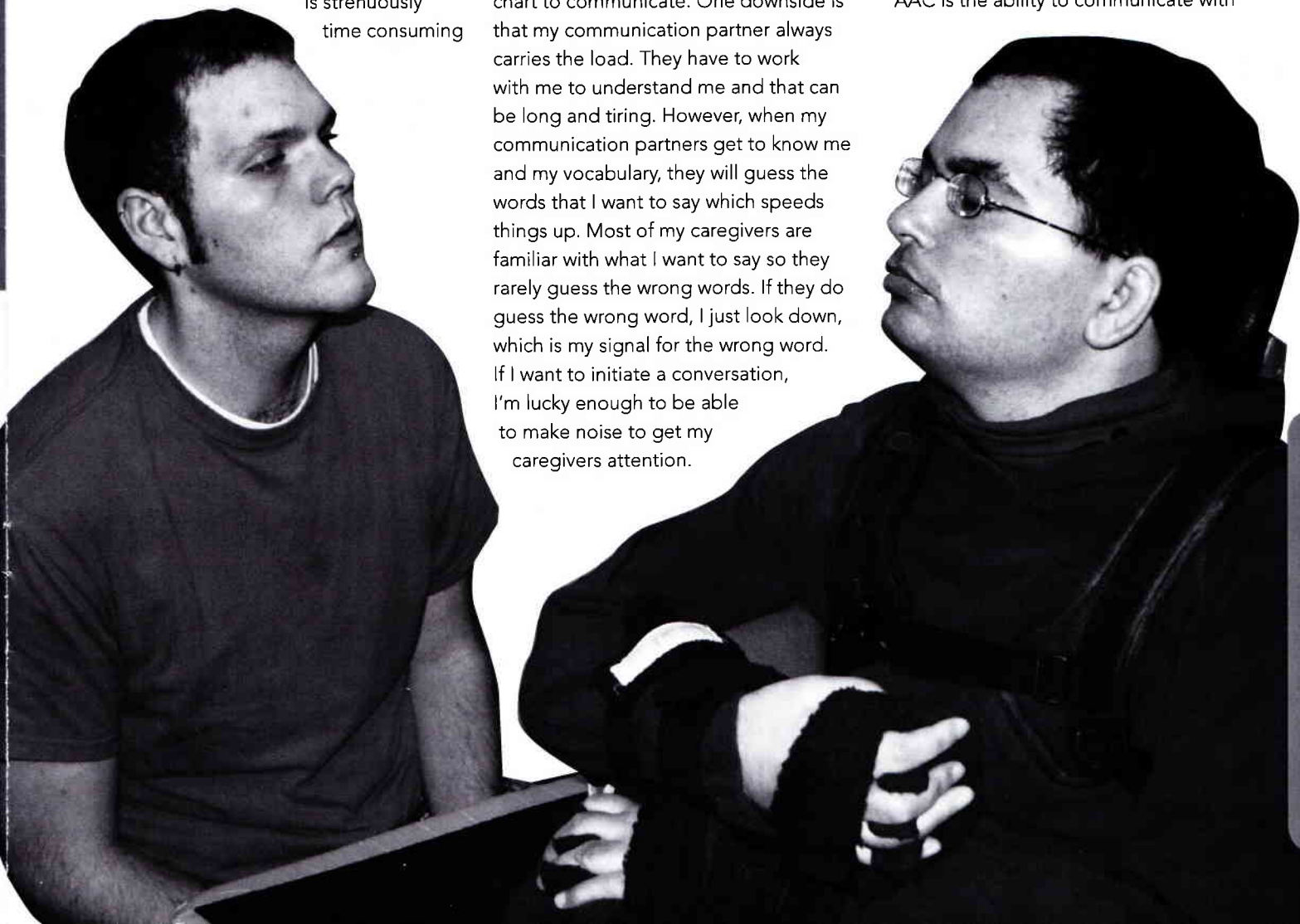
and the user is confined or limited in the conversation.

I feel that using the chart with a partner is much more natural than using a device. Some people feel that using the chart to communicate with me is hard, but I've known people who pick it up in a matter of hours. Over the years, I have learned quite a bit about what it takes for people to communicate with me. My communication partner must be patient, understanding, quick, and thorough. They must speak clearly, with good volume, and enunciate. I have come to realize that the one thing that sets a good communication partner, and caregiver, apart from everyone else is their heart; that they can empathize and understand my situation. In addition, when I'm using the chart to communicate, I need someone who uses logic, pays attention, has a good memory, and doesn't make me feel like I'm just a client and they're just here for the money (see Figure 2). There are pros and cons to using the chart to communicate. One downside is that my communication partner always carries the load. They have to work with me to understand me and that can be long and tiring. However, when my communication partners get to know me and my vocabulary, they will guess the words that I want to say which speeds things up. Most of my caregivers are familiar with what I want to say so they rarely guess the wrong words. If they do guess the wrong word, I just look down, which is my signal for the wrong word. If I want to initiate a conversation, I'm lucky enough to be able to make noise to get my caregivers attention.

If I could speak or type my own messages in a timely manner, there would be one less step in the communication process. It's even more work when there is a third party involved who does not know my way of communicating. During these times, my caregiver also serves as my translator.

Having a good communication partner is essential for me because I interact with society every day. I'm always keeping up with old friends and family on Facebook. I communicate, using the chart, to my caregiver what I want to post and she types out my messages for me. I tend to use the same caregiver for personal correspondences. I also enjoy going out on the weekends with my caregiver/friend Mark. We go out and support local bands, including Mark's band. I enjoy writing long emails to my friends and family who don't live close enough to visit me. Again, I do this activity with my caregiver.

Ultimately, what I feel most people in my position want out of the field of AAC is the ability to communicate with



BRAIN-COMPUTER INTERFACE: **Locked-in and Reaching New Heights**

continued from page 4

people using a system that's quick, convenient, easy to understand, and reliable.

revisiting clinic

After 15 years, I thought it would be a good idea to reconnect with my speech-language pathologist to see what AAC options exist these days for people like me. In the past year since we started working together again, we've tried at least four different devices for writing and social networking. So far, I like EZ Keys the best. I prefer it because it allows me to type my own messages, granted I trade speed for independence. I use an AbleNet Specs switch on a universal switch mount near my right jaw. I can move my head a small amount to hit the switch. I use EZ Keys as a row-column scanning system on a Words+ Freedom 2000 speech device. Not everyone with locked-in syndrome has the ability to move as much as I do, which is what makes a switch more practical for me.

I have tried a few eye tracking devices, but I don't like having to look at a screen between me and my communication partner. And it's much slower than the alphabet chart. Right now, I am not interested in all the other functions that the eye tracking devices would give me because it's just too hard for me to use.

brain computer interface

I was recently introduced to a brain-computer interface (BCI) system, which is under development. The research, funded by a grant from the National Institutes of Health (NIH), is developing a noninvasive brain-computer interface. The research team comes to my home weekly to try the system and work out the kinks with me. It takes me hours to get ready and get to my appointments, so home visits are a real help to me. During visits, I wear a fitted cap (like a shower cap) with electrodes on it (see cover). A

display of letters is flashed on a computer screen in front of me. My brain activity changes when I see my chosen letter on the screen. Letters are chosen to spell words. Currently, I am one of two end users and I get to try out the changes in the BCI computer. I collaborate with the team to develop the system into something usable for the public. This process will likely take years.

It is fascinating to watch development of the BCI system from the ideas to the implementation. I think

it must be frustrating because the team is working from the ground up. I look forward to a time when the BCI computer is on the market for people with disabilities. Throughout this research project, I have had the opportunity to assist the team in understanding things from a user's standpoint. It has shaped my concept of what I think would be most helpful, not only for me, but for others who are locked-in. This has been, and continues to be, a wonderful experience for me.

what I want from bci

At the very least, I am hoping that a BCI system will help me with written communication. I want to be able to express myself without the help of others at all times. If the system were able to predict text based on how my sentences are formed, that would be helpful. I want to be able to write emails and use Facebook independently. I would also like to be able to turn the pages on a book. For people like me who are completely locked-in, it would also be nice to be able to control simple things in my environment like my wheelchair and

the lift on my van. I would like to turn on lights, the thermostat, the radio, and my television. As I work more with the BCI system, I feel that it has the potential to do an unlimited amount of things in the future. This is amazing research and I feel very privileged to be a part of it. This sort of experimenting will lead to great things and drastically change the lives of the disabled in ways that many people never thought would be possible. A BCI has the potential to control a lot, but a

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person who is locked-in will always need to be interdependent. I can see a BCI system being added to the equation, but ultimately I will still need my caregivers.

So far, with all the testing I've done with the BCI team, I feel like my needs for AAC have been met by having a good switch and an appropriate mount for the laptop. However, if I were to go out in public with those things, that would be a major hassle because the laptop mount is too bulky. Perhaps there are other mounts that would be more practical for public use. The most reliable and accurate switch, a more flexible yet sturdy mount, and the screen being at eye level are all very important. I am

concerned about creating a barrier between myself and who I am speaking with. If there was a way to use a screen about the size of a touch pad (not too big, not too small), then that would be better as far as size goes.

recommendations for clinicians

I think the best therapist is one who has empathy and understands your unique situation. And you need to know your equipment if you are going to show it to me. I have an opinion on all the AAC devices that I tried, and my opinion is not good if the equipment doesn't work on the first try!

conclusion

Words cannot express how much I enjoy being included in this life changing research project. Being a part of this team has enriched my life in so many ways. Participating in the BCI study is my way of helping others; not only the researchers, but also others who are locked-in. It makes me feel like I'm really doing something to help those with disabilities who are in a similar position as me. Giving people with LIS the option to use a BCI in their daily life can provide so many benefits. It has the potential to give us a sense of control, the ability to communicate independently, and a sense of depth. The challenges of designing a BCI system for people who are social and intelligent are to make it user friendly, reliable, just as easy and fast as other AAC systems, and unobtrusive. That said, BCI also can open new doors, which is hard to do when you're locked-in.

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Dear Members,

This letter introduces you to a resurrected issue of the vivacious and spirited SpeakUp magazine, and a new USSAAC administration that is equally active and invigorated!

The recent year has been one of restructuring and rebuilding. USSAAC, like most nonprofit organizations is constantly striving to heighten its awareness of stakeholder needs, while balancing the realities of budgetary restraints and the constant dearth of volunteers to address planned priorities. Over the past two years, under the tutelage of India Ochs, this organization has maintained a commitment to developing its membership, most critically in the area of individuals who use AAC; has revitalized this publication SpeakUp; and is working to collaborate with AACI and SHOUT on the planning of the upcoming ISAAC Conference in Pittsburgh, PA in July 2012!

Congratulation and a warm welcome to our newly elected Board members: Chris Klein as President-Elect and Gabe Gibbons, Pam Harris and Gus Estrella as incoming Regional Representatives. I would also like to take this opportunity to thank our many friends and colleagues who have given of their time, energy and other resources to serve on the outgoing Executive Committee and Board of Directors. A special thank you to Tom Reed and Amy Sonntag and all their contributions over the years as Regional Representatives. We will miss your presence on the Board!

This year USSAAC will continue to emphasize the following priorities.

TO INCREASE:

1. membership
2. advocacy activities
3. distribution of the SpeakUp magazine
4. offerings of continuing education units (CEUs)
5. content and usability of the USSAAC website
6. communications to the membership via social networking sites and eBlasts

In order to accomplish these priorities, the EC and Board of Directors will need significant support through volunteerism on the part of members. **I encourage any member with as little as 1 hour a month to volunteer on a USSAAC activity to visit the website at www.ussaac.org and volunteer your time and/or resources.**

As you prepare your calendar for the new year, keep in mind that the Annual Membership Meeting will be held during the 15th Biennial Conference of the International Society for Augmentative and Alternative Communication (ISAAC) in Pittsburgh, PA. Watch for future announcements of the exact date and agenda!

I look forward to working with all of you as we continue to advance USSAAC – and the AAC Community – towards new innovations and growth.

Pat Ourand
Incoming President

USSAAC
The voice of AAC

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inside

Brain-Computer
Interface:
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President's Letter
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