

VISION ACCESS

Volume 10, Number 1

Spring 2003

Copyright 2003 by the
Council of Citizens with Low Vision International.

VISION ACCESS is a journal by, for, and about people with low vision. VISION ACCESS is published quarterly in three formats (cassette, large print, and computer disk) by the Council of Citizens with Low Vision International (CCLVI), a not-for-profit affiliate of the American Council of the Blind. Views expressed in VISION ACCESS are those of the individual contributors and do not necessarily reflect the views of the editor or of CCLVI. All rights revert to individual contributors upon publication.

VISION ACCESS welcomes submissions from people with low vision, from professionals such as ophthalmologists, optometrists, and low vision specialists, and from everyone with something substantive to contribute to the ongoing discussion of low vision and all of its ramifications. Submissions are best made on 3.5" disk in a format compatible with Microsoft Word. Submissions may also be made in clear typescript. All submissions should include a self-addressed stamped envelope. VISION ACCESS cannot assume responsibility for lost manuscripts. Submissions may be mailed to Joyce Kleiber, 6 Hillside Rd., Wayne, PA 19087.

VISION ACCESS is a free publication to all members of the Council of Citizens with Low Vision International. Subscription and membership inquiries can be made to CCLVI's toll free line, 1-800-733-2258.

Editor: Joyce Kleiber

CCLVI OFFICERS:

Patricia Beattie, President,
Bernice Kandarian, 1st Vice President,
LeRoy F. Saunders, 2nd Vice President,
Karen Johnson, Secretary,
Coletta Davis, Treasurer,
Carl Foley, Membership
Ken Stewart, Past President

CCLVI BOARD MEMBERS:

Charles Glaser
Mike Godino
Imogene Johnson
Jane Kardas
Joyce Kleiber
Barbara Kron
Fred Scheigert
Skip Sharpe
Janis Stanger

Contents

From the Editor.....	3
Organization News	
President's Message.....	4
CCLVI Will Enrich ACB Convention!.....	5
Who Calls CCLVI's 800 Line?, by Bernice Kandarian.....	8
Publication Committee Considers VISION ACCESS' Cost.....	9
News from Our Chapters.....	10
In Memoriam, Janet Rae Bossert, By Bernice Kandarian.....	13
Quality of Life	
The New Image of Disability, By Charles Gougey, PhD., MT-BC.....	13
Member to Member, By Charlie Gougey, PhD, MT-BC.....	18
International BiOptic Driving Conference.....	20
Attorneys Sought for Research Study.....	21
IRS Makes Tax Reporting Accessible, By Jane Pic.....	22
Legislative Matters	
Low Vision Therapist Certification: A Personal Perspective, By Janis Stanger.....	23
Disabling Rights for Us All, By Rachel Simon.....	27
Moving Ahead in the 108th Congress.....	29
Medicare Rights Center Launches Consumer Advisory Board.....	30
MCR Answers Some FAQs About Medicare.....	31
Support for Video Description Restoration Act.....	32
Assistive Technology	
Make It Bigger!, By Dawn Wilcox.....	34
Pulse Data and Benetech Announce Collaboration to Make Books Accessible.....	36
Designs for Vision's New Metal Frame Available at Lighthouse Store.....	38
Amazon.com Launches Accessible Website.....	38
People	
Career Officers Told Me It Was Ridiculous to Consider the Stage and Suggested I Become a Typist, By Beverley Kemp.....	39
Request for Contributions.....	42
Resources.....	42
CCLVI Membership Application and Renewal.....	44

From the Editor

Last Friday in a doctor's waiting room, to pass the time, I read the newspaper. I used my Clear Image glasses and held the paper two inches in front of my better eye. I am truly grateful that my vision and my glasses allow me the pleasure of knowing my world through my Philadelphia Inquirer. Suddenly, I was jarred out of my book review! "Who is your eye doctor?" a lady sitting near me asked. She wanted to refer me to a doctor who could help me see better. Her late husband was an ophthalmologist and she was concerned. She was surprised when I told her about my low vision.

We in CCLVI have work to do. Policy makers, people in our lives, in fact most people, know so little about how we live and what we need. These are some of the things we talk about in this issue of VISION ACCESS. It's your chance to become a better-informed advocate for yourself and for others.

And isn't it good to have a relationship with CCLVI and the people in this group! Here we are understood and we don't have to explain ourselves over and over again. CCLVI is working to advance our quality of life.

I invite you to share your experiences and knowledge. Let us hear from you. Thanks to all who contributed to this issue.

At the time of this writing our country is at war. Many people will be injured; some will lose all or part of their vision. We in CCLVI can begin to consider how we can alert military medical personnel about the importance of ongoing information and support for people experiencing vision loss.

JMK, 3/21/03.

Organization News
President's Message

YOU CAN JOIN US IN PITTSBURGH IN PERSON, ON YOUR COMPUTER OR IN THIS PUBLICATION - BUT DON'T MISS OUR CONVENTION!

We are excited to announce details of plans for activities for our 2003 annual convention this summer in Pittsburgh, Pennsylvania. We hope you will travel by plane, train, bus or computer to be a part of our informational, advocacy, support and fun-packed social events beginning Saturday, July 5. As members of CCLVI, you will receive a pre-registration packet in May from our parent organization, the American Council of the Blind (ACB) and learn about many other good reasons for heading for Pittsburgh right after the Fourth of July.

For instant information about the hotels, rates, and other exciting events that will be going on July 5-12, take a look at the ACB Braille Forum that you also should be receiving, check at acb.org on the worldwide web or call 800-424-8666.

Elsewhere in this issue of Vision Access magazine, you will find details of our convention program beginning with events on Saturday and concluding with our Farewell Dance on Friday, July 11 featuring the listening and dancing music of the popular Gordon Kent. In-between you will learn about the current status of low vision services in our country, specialized recreation opportunities, genetics and inherited eye conditions, how to become a part of our award-winning Project Insight telephone mentoring program, and opportunities to participate in model support groups led by two terrific facilitators who have low vision themselves. And, we'll have fun, too - the mixer on Sunday afternoon, our traditional dances on Sunday and Friday nights, and our repeat of last year's hilarious Game Night.

One key reason you might want to come to Pittsburgh is ACB's exhibit hall. You'll get to see the latest in magnifiers, gadgets, computers, cell phones, and exhibits by organizations from across the country and around the world who have things you may not even know exist. The good news is that both the train and bus stations are right across the street from the lead hotel! So if you can't stay for several days, pop in Saturday afternoon and Sunday for the exhibits, Sunday program session, and our mixer. We want to see long-time friends and meet new ones - particularly from folks interested in joining new chapters which are perking in Baltimore, Austin, Nashville and Washington state.

We are working to have some of our program sessions streamed live on the Internet, just like sessions from the ACB convention. But you always can depend on our editor, Joyce Kleiber, to give you detailed reports on the terrific speakers presenting the latest information at the program sessions.

We look forward to seeing you in Pittsburgh - in person, live on the Internet, following up on our website or relying on our magazine. Don't miss the information and options you'll learn about as you live with low vision.

Pat Beattie, President
Council of Citizens with Low Vision, International

CCLVI Will Enrich ACB Convention

Our many presenters are experts and deeply interested in and committed to their work with and for people with eye problems. Here are two examples: Michael B. Gorin, MD, PhD, Professor, Ophthalmology, University of Pittsburgh Medical Center, said that he feels honored to be a part of our convention; he knows about us, subscribes to VISION ACCESS and appreciates our purpose and our work. Kristal Platt, MS, Genetic Counselor, University of Nebraska Medical Center, has low vision, works as a genetics counselor and is a dedicated wife and mother. Just think what it will be like to meet and be inspired by people like Dr. Gorin and Kristal Platt! One of our panels will give you an array of options for healthy and fun-filled recreation. Expand your horizons by meeting people from around the world and from our own country. Support groups, business meetings, parties, games and dances are all part of our program. Come and let us meet you and welcome you!

We will meet at the Convention Center in Pittsburgh, Saturday, July 5, through July 12, 2003.

We thank Bernice Kandarian, CCLVI's First Vice President for developing our program. Here it is!

Saturday, July 5, 2003

3:00 pm to 6:00 pm CCLVI Pre-convention Board Meeting.

6:00 pm to 7:00 pm CCLVI Nominating Committee Meeting.

Sunday, July 6, 2003

"A Well Balanced Day"

9:00 am to 10:15 am Helping the Patient with Central Vision Loss: Diabetes, Macular Degeneration, etc.

Paul B. Freeman, OD, FAAO, Diplomate Low Vision,
Chief, Low Vision Services, Allegheny General Hospital, Pittsburgh, PA.

10:15 am to 10:30 am An Overview of the American Academy of Optometry and the American Optometric Association Low Vision Sections; Kathleen F.

Freeman, OD, FAAO, Diplomate Low Vision, Immediate Past Chair of both sections.

10:40 am to 11:00 am Committee Reports-Nominations, Ken Stewart Chair; Credentials, Coletta Davis Chair; Scholarships (Fred Scheigert and Carl Foley), Janis Stanger Chair; Resolutions, Mike Godino Chair.

11:00 am to 11:50 am The Value of Sports and Recreation for People with Visual Impairment and How to Get Involved;
Panel: Moderator: Ken Stewart; Panelists: Oral O. Miller, President, United States Association for Blind Athletes, Past President, American Blind Bowling Association and Past Vice-President, Ski For Light; Susan Lichtenfels, Founder, SportsVision; Enrique Perrez, President, International Blind Sports Association (invited); Marty Mathews, President, Western Pennsylvania BOLD-Blind Outdoor Leisure Development.

11:50 am to 12:00 noon Reading of Proposed Constitutional Amendments, Michael Byington, Chair.

1:30 pm to 3:00 pm CCLVI Support Group for People Living with Low Vision; Facilitator, Herb Guggenheim, PhD.

4:00 pm to 6:00 pm CCLVI Mixer President's Suite.

10:00 pm to 1:00 am Back by Popular Demand! Music the Way You Like It: Gordon Kent takes requests for listening and dancing.

Monday, July 7, 2003

Cosponsored Session with ACB Human Service Professionals, Council of Families with Visual Impairment, and National Association for Parents of Children with Visual Impairment.

1:30 pm to 4:30 pm Genetic Eye Conditions and Visual Impairment; Michael B. Gorin, MD, PhD, Professor, Ophthalmology University of Pittsburgh Medical Center; Kristal Platt, MS, Genetic Counselor, University of Nebraska Medical Center, Latest information about genetics and eye conditions and how they may relate to other health issues, implications for consumers and parents and how counseling can assist.

Tuesday, July 8, 2003

1:30 pm to 2:30 pm Low Vision Services Around the World; Panel: Moderator: Jane Kardas; Panelists: international guests from Canada, Japan, Mexico, New Zealand, and others. Discover how services for people with low vision differ around our planet.

2:30 pm to 4:30 pm Annual Business Meeting

4:30 pm to 6:00 pm Post-Convention Board Meeting

Wednesday, July 9, 2003

"Giving and Getting Support"

1:30 pm to 3:00 pm Project Insight Volunteer Training, Joyce Kleiber, LCSW, Coordinator, Training session for current and prospective mentors in CCLVI's award-winning telephone support network.

3:00 pm to 4:30 pm CCLVI Support Group for people living with low vision; Facilitator, Charles Gourney, PhD.

7:30 pm to 10:00 pm CCLVI Game Night, Team Trivia, Name That Tune!, Dating Game, Marriage Game and More!

Friday, July 11, 2003

10:00 pm to 1:00 am Farewell to Pittsburgh Dance with the music of Gordon Kent, one-man orchestra.

Note: Check Registration Packet for applicable fees.

Who Calls CCLVI's 800 Line?

By Bernice Kandarian

I answer calls to CCLVI's 800 Line live from 9am to 4pm Pacific Time Monday through Friday and at other times if I am available. But not at 2:30 am, contrary to some people's apparent belief that we are a 24-hour operation. Here are some examples of the types of calls we receive on our 800 line:

Requests for information on macular degeneration, about half from the individuals themselves and half from family members or friends: I refer then to Macular Degeneration Partnership and Macular Degeneration International, send them an NEI booklet "What You Should Know About Low Vision," a MacPac from the Health Library, etc.

Scholarship requests: For the Fred Scheigert Scholarship, I screen applicants for potential vision eligibility and ask them to send a self-addressed stamped envelope to Janis Stanger, our Scholarship Committee Chairperson; I refer Carl Foley Scholarship applicants directly to Carl.

Requests for medical information about various eye conditions: I refer these callers to the Health Library, if they have a diagnosis; the Health Library provides the information to them in preferred medium--large print, e-mail, cassette or Braille.

Requests for referral to low vision doctors: I refer to low vision clinics or the Lighthouse in New York City, where a database of low vision doctors is being developed.

Occupational and physical Therapists who want information about devices and services, for example, directory assistance exemption, library services, etc I send brochures for their patients and a complimentary copy of Vision Access.

Requests for equipment and supplies related to low vision: I provide sources of mail order products. We are working on a list of resources for our website.

Requests for help purchasing glasses: I refer to Lions' Clubs and Eye Care America.

Parents of visually impaired children looking for information and support: I refer to NAPVI (National Association for Parents of Children with Visual Impairment), early intervention programs and organizations such as Blind Babies Foundation in San Francisco.

People updating our listing in directories and databases, such as libraries, Independent Living Centers and County Offices on Aging.

People looking for support groups or mentors: I try to match these callers with our Project Insight volunteers.

People wanting information about CCLVI, including Vision Access and/or brochures.

Some days it's call on top of call and some days the phone hardly rings. Some calls are very short, while some require much time and/or research. People often say that this is the first place they have called where they have received useful information. The 800 line continues to be an important service that puts CCLVI on the map.

Publication Committee Considers Vision Access' Costs

The Publication Committee-Janis Stanger, Ken Stewart, and Joyce Kleiber-- met to consider the production of VISION ACCESS, especially the costs involved in printing and recording this magazine. These costs make up one of the largest expenditures in CCLVI's budget. Here is how VISION ACCE SS is published

After VISION ACCESS is put together and edited on a computer, the final version is emailed to our printer, Minute Man Press in Pittsburgh, PA. There Andy Booth makes a digital copy of our magazine from which he prints the required number of copies in 14 point font. Andy then attaches address labels to each copy and takes these to the Post Office in Pittsburgh. The cost for printing, labeling and mailing is about \$3. per copy.

Ray Fournier of Diamond Tape Productions in Sanford, Maine produces our cassette version. Ray hires a reader certified by the National Library Service, who spends three to four hours of studio time reading VISION ACCESS onto tape. While he is reading, Ray is in the studio listening for needed editing of the text. Then Ray transfers the recorded material onto a master duplicating tape from which he makes copies of the cassette edition of VISION ACCESS. He places the cassettes into mailing envelopes to which address labels have been affixed. The cost to CCLVI for this service is \$400 per issue of Vision ACCESS. This covers the cost of the cassettes, salary of the reader, cost of studio time, editing, mastering and mailing.

The Publication Committee strongly recommends that CCLVI members who have access to email consider obtaining their magazines via email. Since there is no cost for this email version, readers who choose this option will contribute to CCLVI's fiscal stability; this will free funds for other endeavors, including CCLVI's 800 line, Project Insight development, and other worthwhile programs. Readers can receive email versions of VISION ACCESS by sending a blank message to: visionaccesssubscribe@yahoo.com. Contact CCLVI at 800-733-2258 to let us know if an email edition of VISION ACCESS is right for you.

The Publications Committee welcomes other suggestions.

News from Our Chapters

California Council of Citizens with Low Vision, CCCLV.

This Chapter, under the direction of President Bernice Kandarian and in collaboration with the California Council of the Blind, planned an excellent Spring 2003 Convention Program. Members met from April 10 to 12.

Molly Story Coordinator of Research at the Center for Universal Design, North Carolina State University spoke about making appliances more useable and about access to medical devices and services.

Then Bob Planthold, Co-Chair Pedestrian Safety Committee of Senior Action Network and Arthur L. Singer, Esq., Attorney at Law and Member of the California Council of the Blind Advocacy Committee considered "Pitfalls to Technology: The Segway: A Case Study."

William Wade, Federal Security Director and Transportation Security Administration, Sacramento International Airport, talked about the latest screening procedures and requirements at U.S. Airports.

In a Joint Session with California Council of the Blind's Committee on Senior Blind chaired by Bonnie Rennie, attendees considered services to seniors by the Department of Rehabilitation, DOR. The speaker, Jim Armstrong, Program Manager, Blind Services Division, also gave people the chance to give their feedback about such services.

Attendees then learned about The Senior Intensive Retreat Program, a new short-term residential daily living skills experience. Brian Bashin, Executive Director, Society for the Blind, Sacramento, CA, was the presenter.

Then, Tim Ford, Attorney, Department of Health Services, Sacramento, CA, talked about Access News and News Line for the Blind, what they are and how they compare.

Then Dawn Wilcox, RN BSN and Jean Ackerman, RN MSN of The Health Library spoke about Access to Health Information for People with Vision Loss.

Finally, Barbara Kron and Jane Kardas described "Project Insight--what it can do for you and what you can do for others,"

For information about the California Council of Citizens with Low Vision call 800-733-2258.

Metropolitan Chapter of Low Vision Individuals. MCLVI continues to focus primarily on advocacy regarding transportation issues. For further information about this chapter, which serves the New York City Metropolitan area, contact Ken Stewart at 845-986-2955.

Nation Capitol Chapter. NCCLV members elected and welcomed the following new officers and board members: President--Barbara Milleville; Vice President--David Johnson; Corresponding Secretary--Skip Sharpe; Recording Secretary--Sarah Presley; Treasurer--David Lingeback; Board Members--Kilof Legge and Tracy Soforenko.

Despite it being the coldest day of the year, we had a nice crowd show up to hear Rich Krafzig from Pulse Data HumanWare speak to us about a global positioning system (GPS) that's specifically designed for folks with visual impairments. The group learned that the GPS will be a good piece of assistive technology for most of us when the next version comes out

A President's Day weekend storm dumped knee-deep snow on the DC metro area and caused us to postpone the February meeting. We met in March and folks from H&R Block shared some money-saving tax tips from a disability perspective. We all learned that it makes good "cents" to know what tax programs benefit people with disabilities and to keep track of medical expenses and donations to charitable organizations.

Our regular March event featured Arnold Passman, from Live Safe America. A former police and fire officer, Arnold spoke on safety issues that folks with disabilities might encounter. Although this is not typically a "fun" topic, Arnold's true stories and practical tips on how to be safe and get our needs met at the same time entertained people who came. One of the most valuable things we learned was to yell loudly, "GET AWAY FROM ME!" if strangers approach and act like they are going to do something to hurt us. The meeting was co-sponsored by EXCEL!, a networking organization for people with disabilities seeking employment. Everyone had a good time mingling with the gang after the meeting.

We at NCCLV love to see old and new faces at the meetings. Join us sometime soon! For information email: NCCLV@yahoo.com.

Other CCLVI Chapters

Delaware Valley Council
(Philadelphia and Southern New Jersey), 215-735-5888

Florida Council
800-267-4448.

In Memoriam

Janet Rae Bossert

February 21, 1938 - February 27, 2003

By Bernice Kandarian

Jan, as she was known, was the beloved wife of CCLVI Past President, Ira Bossert. With her help, Ira established one of the first walk-in stores in the country featuring products for people with impaired vision.

Jan was an active member of CCLVI and Ira's supportive partner during the time that his vision was declining. She was interested in developing a group for spouses and significant others of people who were experiencing vision loss. She published a booklet on this subject, "The Other Side of the Fence."

Quality of Life

The New Image of Disability

By Charles Gourgey, Ph.D., MT-BC

[Note: This homily was given at a worship service during a retreat at Montreat Conference Center, Montreat, North Carolina, in November, 2002. The theme of the retreat was "Foundations of Mutuality: Beyond Us and Them."

This essay represents the Judeo-Christian perspective. We invite people from other Faith traditions to share how their spirituality informs their self-concept/disability.

"Do not lie to one another, seeing that you have stripped off the old self with its practices and have clothed yourselves with the new self, which is being renewed in knowledge according to the image of its creator. In that renewal there is no longer Greek and Jew, circumcised and uncircumcised, barbarian, Scythian, slave and free; but Christ is all and in all!" (Colossians 3:9-11)

We have spoken a lot this weekend about images of disability: images of disability in the Bible, in society, in our congregations. But we also need to confront the most powerful image of all: the image we have of ourselves as someone who is disabled.

An incident that occurred several years ago, as insignificant as it was, has never left my memory. I was approaching the entrance to a museum when I saw a person in a wheelchair waiting to get in. I held the door open for him. He yelled at me as if I had assaulted him. Apparently my sin was to offer him assistance he did not explicitly ask for.

I often wondered, Why was he so upset? After all, my intentions were good. I didn't think I was guilty of bad manners; on the contrary, I was trying to be polite. I didn't mean to insult him. But then I realized the episode wasn't about me, it was about him. Without knowing it he was telling me how he sees himself: as someone contemptible and helpless, always treated like a child. He was showing me his image of himself as a disabled person.

It is easy to acquire a negative image of ourselves because of our disability. We form our self-image largely based upon feedback we receive from others. And people often do see our disabilities as signs of inferiority. If you are disabled, has anyone ever addressed the person next to you when the question was really meant for you? How does it make you feel when the waitress asks your partner, "Now what would your friend like to order?" How does it make you feel when someone speaks to you in a loud, slow voice when your disability has nothing to do with your hearing or your comprehension? Or when someone speaks to you as if you were still a child? If you were disabled since childhood, were most of your friends disabled too?

Unless we are very conscious - a consciousness that only comes to us in adulthood - every encounter like this affects our self-image. We have confronted the images of disability all around us. We must also confront the images of disability within ourselves.

No one can stand having a negative self-image. It makes us angry, mistrustful of others, insecure, unsure of ourselves. It creates a vicious cycle: not at peace with ourselves, we push people away, and the feelings of rejection and isolation that result only worsen our self-image. Not everyone experiences these effects the same way, but people who are disabled are especially at risk.

So this is the first part of our task of spiritual renewal: to look within ourselves and to recognize the negative self-image. This part requires courage, because it means facing our inner darkness. We can come together, share our stories, show each other support, teach each other through our own experience, but in the end it is up to each one of us to do this work for ourselves.

And the work does not stop here. We need much more than just the ability to see the darkness. No one can live in total darkness. Without faith there is no life. We need to find our way back from darkness to faith.

If the image we have acquired of ourselves has made us dwell in darkness, then from where does light come? Jesus called himself the "light of the world" (John 8:12). There is a whole literature on the "imitation of Christ." Can we find a better image of ourselves by adopting the image of Christ?

Perhaps a few saintly people can do it. For most of us, it may be too big a jump. We cannot see ourselves as Christlike in our present condition, and to attempt it may only throw us into deeper despair. We need a place to begin that is "accessible" from where we find ourselves right now.

That place, paradoxically, is within ourselves.

The Bible tells us we each were created in the "image and likeness of God" (Genesis 1:27). But there is more: since God is infinite, each "image" is unique. The Talmud puts it like this:

"Humanity was produced from one man, Adam, to show God's greatness. When a man mints a coin in a press, each coin is identical. But when the King of Kings, the Holy One, blessed be He, creates people in the form of Adam not one is similar to any other." (Mishnah, Sanhedrin, 4:5)

The image of light we must grasp to escape our darkness is different for each one of us. So ask yourself: When God created you, what did God create? God created in you a being capable of love, with a unique individuality and a purpose that no one else can fulfill. We need to see ourselves through God's eyes, to see ourselves as God knows

us, rather than as the world has seen us and fed us back to ourselves. The two could not be more different.

Recently in the hospice where I work I met a very spiritual lady, a friend of one of my patients who was also a Christian missionary. She had one word of advice for me: "You must know your name."

What is our name? Our name is transmitted through our parents but given to us by God. And sometimes it is actually God who reminds us of our name. When the angel asked Jacob "What is your name?" Jacob answered, naturally, "Jacob." The angel said "No, that is not your name. Your name is Israel, the one who strives with God" (Genesis 32:27-28). Through his own struggle Jacob had to learn his name, and once he did, no one could shake his sense of identity.

Do you know your name? It is a name no one else has. If you know your name, then no one can hang a false image on you. Ask yourself in the privacy of your heart, "What is my name?"

The great Dominican mystic Meister Eckhart had a saying, for which he was actually prosecuted for heresy:

"The eye with which I see God is the same eye with which God sees me: my eye and God's eye are one eye, one seeing, one knowing and one love." (German Sermon No. 12)

We need to see ourselves through the eye with which God sees us. And that means seeing ourselves through eyes of love.

This is not a simple exercise. It takes time and devotion, meditation and prayer. It requires that we develop a kind of spiritual perception. Can we see through the false images, the stereotypes, the layers of human distortion, to behold the soul as fresh as God created it?

The very first words that an observant Jew says on praying each morning are: "My God, the soul that you have given me is pure." Can we see the purity of our soul? Of our soul, not somebody else's? Can we behold our own individuality, our own talents and gifts, our own loving nature, the best that God has given us? This is the unique image given by God to us and to no other. This is the image we must hold in front of ourselves until we actually become that image, free from the bondage of the impressions, attitudes, and beliefs that have come to form the self we only think we know.

"For all who are led by the Spirit of God are children of God. For you did not receive a spirit of slavery to fall back into fear, but you have received a spirit of adoption." (Romans 8:14-15)

The slavery that pushes us back into fear is the slavery of accepting the images with which we have been tagged, first by those around us, then by ourselves. The spirit of slavery is a false spirit. The true, saving spirit is the spirit of adoption as children of the Creator, who has given us a soul that is whole, pure, and without any disability.

Whether or not you are disabled, can you see your soul as God created it? Can you see the individual gifts that God has given only to you? It is not important that you feel like that person right now, but only that you are able to see the image, to picture it, to hold it in your mind. That image is who you will become, as you receive your spirit of adoption and know yourself as God knows you. That is the new image, the "new creation" of which the Bible speaks (2 Corinthians 5:17). If you feel like you are still living in the darkness of an image you cannot accept, then hold in your mind the light of this new image, the pure soul God has given you, until you really begin to see it and become it.

This is how we strip off the old self and clothe ourselves with the new one. The old self, the negative image given to us by society, by the people around us, by portrayals in the media, by bigoted attitudes that seem so resistant to change, need no longer rob us of our dignity. When we know ourselves as God created us, then images in the

minds of others will no longer matter. But it won't happen tonight and it won't happen tomorrow. We will be guided towards it, but it does not come without effort and commitment. But when it does come we will find ourselves passing through barriers that have kept us apart and feeling like outsiders.

It is so important to build bridges and to cross those barriers. That is why the scripture states, "There is no longer Greek and Jew, circumcised and uncircumcised, slave and free," and perhaps we are also entitled to add, even disabled and non-disabled.

Charles Gourgey's web site, <http://www.judeochristianity.org/>, contains more material with the same spiritual orientation.

Member to Member **By Charlie Gourgey, PhD, MT-BC**

Every so often within the disability community the issue of what we should call ourselves arises. Many terms have been used to describe us: "handicapped," "disabled," "differently abled," "people with disabilities," "physically challenged," and even "people with exceptionalities." No one term seems to satisfy.

One national disability organization has proposed inventing a completely new term and has called for submissions. They want a term that avoids the negative implications associated with disability. Since the term "disabled" seems to imply the inability to do things, a completely different term would, according to them, serve the interests of our community better and minimize prejudice.

We discussed this issue at length in our electronic support group, and while opinions differed, for the most part our members disagreed with that sentiment. Here are a few of the responses:

Changing the word disability has been in the wind for several years. Although it has been the least offensive of all the "definitions" that we have been labeled with, "dis" in all its well-meaning forms is still negative. The problem is coming up with something positive but not cute, euphemistic, or coined by the non-disabled service providers. Sooooooo, with all your great journalism education, feel free to knock around a few terms.

When the term "disabled" first emerged as an alternative to "handicapped" I didn't like it. The word literally means that you can't function effectively, that you've lost your ability. To "disable" something means to make it inoperative. An even worse image than "handicapped," which only implies a disadvantage, rather than a loss of ability.

However the use of the term "disabled" has become so common now that I don't believe people even think about its meaning. Changing it now would be too much of a hassle. And all the alternatives I've heard ("differently abled," "challenged" one way or another) just sound silly to me.

I'm not sure I agree with the idea of making up brand new words to replace "disabled" and "disability." These terms are certainly better than "handicapped" and "handicap," which are still very much in use. It seems to me that made-up words would complicate matters in terms of legislation. And, to be honest, I have no problem with "disabled" and "disability." I think they are quite dignified.

I guess that like everything else, one size doesn't fit all. We're all comfortable with different things. To me, the word "challenged" sounds euphemistic. Of all the terms recently in use, I think I would prefer "person with a disability," although none is really perfect.

I think the reason none of them works is not because of their literal meanings but because of their connotations. And what these words connote is determined by social attitudes, which still need to change.

For a long time I didn't like the term "disabled" either, because the first thing that would pop into my mind when I heard that term was a broken-down VCR that can't be repaired or someone who is helpless. But when I hear the term "physically challenged" I right away think of a person who is successful who just happens to have a disability. The term "conquerable" also goes through my mind when I hear the term "physically challenged. Even though I prefer the term "physically challenged," I often use the term "disabled" because it is more common and I now feel less threatened by it.

I don't see how you can come up with something positive to describe what essentially (let's face it) is a negative without sounding patronizing. The meanings of words change with the times and with social attitudes. If "disabled" had been the original term later replaced by "handicapped," we would all be saying what an improvement "handicapped" is.

So it may not matter a whole lot what the word is, as long as attitudes improve. (Exception: anything euphemistic or condescending will be likely to irritate.) Still a long way to go.

Conclusion: It is not the word itself that matters so much but the attitudes of people around us, as well as our own attitudes towards ourselves. The fact of having a disability confers no intrinsic advantage, so there is no point in pretending otherwise. If we respect ourselves, then the words people use to describe us - even words like "disabled" - will become respectable.

International BiOptic Driving Conference

The program committee of the International BiOptic Driving Conference invites your participation in this important international conference to be held in London, England July 4th - 6th, 2003. The conference is being organized with the purpose of bringing international discussions to the issue of driving with BiOptic telescopes for individuals with low vision. It is also the intent of the program committee to provide the stimulus, through research and clinical presentations, for more aggressive efforts for rigorous research in this important area of visual functioning. Most importantly this conference is also intended to raise public awareness of driving and visual impairment issues.

The conference will have invited speakers covering the areas of personal experiences of being a visually impaired driver, visual impairment and clinical aspects of driving performance, instructional protocols with behind-the-wheel experiences and legislation / standards for obtaining licensure.

It is anticipated that this conference will attract both vision professionals and consumers (adolescents and adults who are visually impaired and who do not have a driver's license). The program committee encourages abstracts for presentations to be submitted from vision researchers, low vision clinicians, medical professionals, low vision association members, driving instructors, orientation and mobility

specialists, licensing bureau officers, individuals who are visually impaired with personal experience in this area they wish to share, and anyone else interested in the topic of BiOptics and driving.

For further information contact Dr. Randy Jose: rjose@uh.edu and visit www.biopicdriving.org.uk Randall Jose, OD, FAAO, Head of Program Committee, Director, Center for Sight Enhancement/University Eye Institute, University of Houston/College of Optometry, 505 J. Davis Armistead Bldg. Houston, TX 77204-2020 USA T: 713 743 0799 F: 713 743 0190

Attorneys Sought for Research Study

If you are an attorney (practicing or not) with vision difficulties (low vision, legally blind, blind, or other visual impairments) that functionally impact your reading (whether reading speed, endurance, tracking, etc.) and you have worked or are working in a law firm that uses billable hours, your participation in this research study is welcome. Columbia University is the sponsor of this study of billable hours and reading.

Study Purpose: This study will investigate and document what impact, if any, the billable hours system has on attorneys with visual difficulties that affect reading. This study will explore whether and how visual difficulties affect attorneys' at firms, how attorneys handle and adjust to any challenges they face on the job due to visual difficulties, as well as how firms respond to attorneys whom they believe or know have visual difficulties.

Participation in this study involves a confidential interview with a researcher. The interview will take place on the phone or at a location convenient to you. Everything participants tell researchers will be kept strictly confidential.

To participate in this Columbia University Institutional Review Board approved study or if you have questions regarding participation, please contact Amy Lowenstein, AEL2004@columbia.edu, Tel. (917) 975-1186

IRS Makes Tax Reporting Accessible

By Jane Pic

The Internal Revenue Service has good news for people with visual impairments to help them retrieve information and file their taxes online next year.

The IRS Web site will be accessible for people who use special assistive technology. The IRS employs 1,100 individuals who are blind or have low vision.

A new software has been developed that will let the standard talking text services, used by people with low vision, read forms stored in a personal document format, or .pdf. Someone with the screen-reading software could click on the "talking" version of the 1040 EZ tax form on the IRS Web site, and the software will begin to read the first line of the form in electronic monotone. The individual then has the option to fill in the form by voice or by typing in the answer.

Although not available for this tax season, the IRS hopes to have 50 of the most common forms in "talking" format for next tax season.

Special assistance is available for people with all types of disabilities. If you are unable to complete your return because of a physical disability, you can obtain assistance from an IRS office or the Volunteer Income Tax Assistance program sponsored by the IRS.

Telephone assistance for the hearing impaired is available for individuals with TTY equipment. The toll-free number for this service is (800) 829-4059 and is available 24 hours a day.

People without this equipment may be able to obtain access through the federal or state relay services (888) 699-6869.

Braille materials for the visually impaired are available at any of the 142 regional libraries in conjunction with the National Library Service for the Blind and Physically Handicapped. To locate the nearest library in your area, write to the National Library Service for the Blind and Physically Handicapped, Library of Congress at 1291 Taylor St., Northwest, Washington, D.C. 20542.

For additional information on services for individuals with disabilities, there are several IRS publications: Tax Topic 101, Publication 910 and Publication 907. Call the local IRS Taxpayer Advocate office at (504) 558-3001.

Jane Pic, mother of a daughter with Down syndrome, writes about issues of interest to people with disabilities. Write to her at P.O. Box 9062, Metairie, LA 70055; or send e-mail to jpica@msn.com.

Legislative Matters

Low Vision Therapist Certification:

A Personal Perspective

By Janis Stanger

The purpose of this article is to tell you about my experience with low vision therapist certification, and to pose some questions on certification in general.

For over twelve years I have worked as a professional in the field of low vision rehabilitation. Until recently, my job title was "Low Vision Advisor." In that capacity I was responsible for pre-and post-clinic training and assessment. Before clients came to the low vision clinic appointment, I conducted patient history interviews, assessed lighting and glare in homes, schools, and job sites, instructed clients in how to use their remaining vision without the use of low vision devices, and made referrals to other agency and community services. After the low vision clinic appointment, I provided training in the use and care of low vision devices, made suggestions for environmental modifications, such as color, contrast and texture, which would enhance the functioning of the client with low vision, and trained the clients in how to best use their remaining vision in conjunction with their low vision devices.

Although I had completed secondary teaching programs at two different universities, a year of graduate work in special education, and completed the course work required for an endorsement to teach the blind and visually impaired in the public schools of my home state, some of the most important training I received for my job as Low Vision Advisor, came on the job. I worked closely with our low vision clinician, who, at one point, served as President of Division Seven-low vision-- of AER (Association for the Education and Rehabilitation of the Blind and Visually Impaired) and had worked closely with others in the field of low vision rehabilitation in developing the test for certification of low vision therapists by ACVREP (Academy for Certification of Vision Rehabilitation and Education Professionals).

I enjoyed my work in low vision rehabilitation, and when the low vision clinician told me he was leaving the agency, and after some serious soul searching, I decided to apply for his job when the opening was announced. I had observed him many times in the clinic setting, he had often told me I had a sound understanding of low vision

rehabilitation, and he occasionally sought my advice or asked for my insight as a person with low vision. I was hired to fill his place as low vision clinician, or as it is called at my agency "Low Vision Specialist." Shortly after being hired to fill this position, questions started to arise about my certification as a low vision therapist. Our former clinician had often encouraged me to sit for the exam, and now that I was in a lead position at the agency, I felt it was time to do so.

Research revealed that there was more than one certification program available. I could be certified by a specific distributor of low vision devices, I could be certified by an organization which certified ophthalmic and optometric assistants, or I could be certified by ACVREP.

The quickest way to certify would be with an individual distributor of low vision devices. I recently participated in training which is presented by Eschenbach, a distributor of optical quality magnifiers and other low vision devices. This training included three days of in-person instruction and two days of observation in a clinic setting.

A certification course for those who want to be optometric or ophthalmic assistants is also available, and the agency where I work has approved this training which is slated to take place in the near future. Our consulting optometrist and ophthalmologist are to be available to provide any assistance I might need to complete the course.

The third avenue of certification is ACVREP. ACVREP has a web site, which contains a copy of the Low Vision Certification Handbook. Looking at the handbook, I saw that the scope of practice for the Certified Low Vision Therapist was very much in line with what I had been doing for twelve years. With that in mind, I felt I was qualified to apply to sit for the exam. However, a closer look at the handbook indicated that I needed to have a degree in education, health, or rehabilitation. Nonetheless, undaunted, I applied. I had, after all, certified to teach on the secondary level, I had completed all the coursework for an endorsement to teach the blind and visually impaired, and I had an additional year of graduate work in special education. And almost twelve years experience in the field. I was denied. The denial letter stated that when I got a degree in education, rehabilitation or health, I could re-apply. This experience with ACVREP has caused me to think a lot about the certification process. After all, I have two brothers who have degrees in education, and I have a sister-in-law who has a BS in nursing. None of them know one single thing about low vision rehabilitation, but all three of them are eligible to sit for the ACVREP Low Vision Certification exam. I even work with some rehabilitation counselors, all of whom have degrees in rehabilitation, who have little more than a surface knowledge of low vision rehabilitation, and yet they too can sit for the ACVREP exam. When I look at these three programs and think back on my secondary teacher certification, with it's requirement of 8 weeks observed student-teaching experience in all three of the areas in which I was certified to teach, I am caused to wonder where the practicum is in these programs. Eschenbach's program is the only one which allows for observation in the job setting, and that is for two days only. What role should practical experience play? Is it really true that my two brothers and my sister-in-law with their degrees can sit for the exam and I with my twelve years of experience cannot? Is that appropriate? I read an article by Chris Grey, President of ACB in the Winter Braille Forum, in which he discussed certification and accreditation. He expressed the belief that something must not be "about us without us." In the certification of low vision rehabilitation professionals, we must play a role as well. Those of us with low vision need to speak out to organizations such as ACVREP and make our concerns known. We need to look at this organization, and others who certify people who provide services for us and make sure that they know we value experience as much as education. We need to insist that those who are certified to provide a service to us actually have experience in the field,

and we need to advocate for changes in certification regulations to insure that those who do have experience in the field are not denied the opportunity to sit for the certification exam simply because they choose to work with secondary students in the education system, or with adults. This may seem to some to be a self-serving position. It may well be. After all, the title of this article warned that it would contain a "personal perspective." I simply believe that those with experience should be allowed to take the certification exam. If their test score merits certification, then certify them. If their test score does not merit certification, then deny them certification. In e-mail correspondence I have had with Sharon L. Milkrut, president of ACVREP, I recently learned that new guidelines are being set for certification. Now is the time to let your opinions be heard. Ms. Milkrut's contact information is Sharon L. Milkrut, President, ACVREP, 4633 N. 1st Ave, Tucson AZ 85718. The ACVREP telephone number is (520) 887-6816. Or you may e-mail her at smilkrut@acvrep.org. If you believe this is all just self-serving, bear in mind that if those with low vision do not speak out about the services they need, those services will not exist.

Disabling Rights for Us All **By Rachel Simon**

Note: This essay appeared in the Philadelphia Inquirer's Commentary Page. It is reprinted with permission.

So you don't have a disability, and you're not, like me, related to someone who does. You might think that the nomination of Jeffrey Sutton to the Sixth Circuit Court of Appeals doesn't mean a fig to you. You'll never get in a car accident that leaves you with traumatic brain injury, or give birth to a child without sight. And laws prohibiting race, gender and religious discrimination are not something you have needed to use.

But Sutton - and the reason people like me are fiercely opposed to his nomination - should mean a huge amount to you. He's a portent of things to come should the Bush administration continue its trend of nominating federal judges with a states'-rights agenda - especially Circuit Court judges, who are seen as being prime candidates for the Supreme Court.

Jeffrey Sutton is the country's most prominent crusader for federalism, a growing movement in which states are increasingly asserting their sovereign immunity from lawsuits based on federal laws. As Ohio state solicitor and partner at a major law firm, Sutton successfully used federalist arguments to restrict Congress' authority to enact civil-rights laws, including the Americans With Disabilities Act.

The way those of us in the disabilities community see it, Sutton's zeal for states' rights is systematically dismantling the ADA and other civil rights laws. As a result of his arguments in *Garrett v. Alabama*, decided by the Supreme Court in 2001, folks with disabilities can no longer sue state employers under the ADA. So Patricia Garrett, a former director of nursing at the University of Alabama-Birmingham Medical Center who was demoted because she had breast cancer cannot take the hospital to court under the ADA.

This ruling curtailed the intent of the ADA, and limited the options for redress available to people who, historically, have already been denied most options to begin with. Sutton's arguments in other ADA cases would have limited people's rights even further, had the courts accepted them.

How unfortunate for Garrett, you might say. But you're not planning to get cancer. And maybe it doesn't matter to you that, if Sutton were a federal judge, people like my sister, who has mental retardation, could be excluded from any state-run programs or services, including health care, education, public transit, and public buildings - and might not be able to sue to contest such egregious discrimination.

Maybe you're not particularly interested in Sutton's other federalism cases either, the ones that had nothing to do with disability. Like the one he was hired to take for Florida, which resulted in part of the Age Discrimination in Employment Act being declared unconstitutional. Or the one in which a Virginia Tech student who was raped was not allowed to pursue her claims under the Violence Against Women Act. Or the one in which Alabama successfully argued that racial and ethnic minorities had no right to challenge disparate-impact discrimination.

But maybe, by just getting Sutton on your radar screen, you see that states' rights is a perilous road. If states are not held responsible for laws passed by Congress, then each state essentially makes its own rules.

Sutton might have argued or filed amicus briefs in the vast majority of recent Supreme Court cases that have curtailed individuals' abilities to enforce their civil rights. But he is not the only federalist being considered for a federal judgeship. Bill Pryor, the Alabama attorney general who champions states' rights, is being considered for nomination, too.

Look out. If you rely in any way on your state - you're employed by your state, receive state-administered health care, attend a state university, or send your child to public school - and you happen to live in a state that doesn't wish to comply with federal laws, your remedies might be drastically curtailed. The federal government may still be able to initiate a suit on your behalf, but such enforcement is rare. You better start packing your boxes now.

A federal judgeship is a lifetime appointment. For Sutton, that means this position, and his agenda, could last several generations. After all, he is 42. The same age as my sister. He could have a profoundly influential career ahead of him. And people like my sister could, because of his career, have options that end right now.

Rachel Simon is the author of "Riding The Bus With My Sister."

Moving Ahead in the 108th Congress **A Memo from the National Vision Rehabilitation Cooperative**

With the 108th Congress underway, we have geared up again to pass the Medicare Vision Rehabilitation Services Act. The legislation will be reintroduced very soon. Our efforts build on the excellent progress made in the last Congress:

- * Cosponsorship of 135 members of the House of Representatives, from both political parties.
- * First-time introduction of a companion bill, in the Senate, which gained 14 bipartisan cosponsors.
- * Nearly 1000 letters, countless phone calls, visits, and other contacts YOU made to your own Congressional delegations. This had a major impact.
- * Endorsement of the bill by more than 70 national, state, and local organizations in the vision, aging and health care fields.

Thanks to your active involvement, our bill achieved impressive broad support in Congress. Not only are House and Senate members now aware of the importance of vision rehabilitation services, but they are now actively discussing how to improve Medicare coverage for those services.

Please visit www.MedicareNow.org often! We will need your sustained help to ensure that Congressional attention to vision rehabilitation continues and grows, and that our legislation is passed in the 108th Congress.

Medicare Rights Center Launches Consumer Advisory Board

To strengthen the voice of consumers in local, state, and national health care policy, the Medicare Rights Center (MRC) has launched a National Medicare Consumer Advisory Board. The board is currently comprised of 35 men and women with Medicare from 23 states, and will expand over the next year to focus on policy affecting access and affordability.

Consumer Advisory Board (CAB) members work in partnership with MRC staff to exchange information on Medicare issues and develop policy positions for communities, the media, and elected officials. Through regular teleconferences, the members advise MRC, a national not-for-profit consumer group, on emerging health care concerns in their communities. Each CAB member coordinates outreach and direct action efforts, from testifying at public hearings to writing letters to local papers. CAB members also conduct state-specific research, identify Medicare consumer forums, and partner with local senior and health care advocacy groups.

"The consumer voice is frequently the last voice heard in the national health care debate," said MRC President Robert M. Hayes. "We intend to change that."

CAB is currently developing strategies in anticipation of the 108th Congress in January 2003 and will work to improve public education on eligibility for Medicare Savings Programs, which help people with limited incomes with their health care costs. CAB members have met with their federal elected officials during the last Congressional recess.

CAB members comprise a diverse group, representing retirees from a variety of fields including education, health care, labor organizing, and the arts. Nearly all are active members of community-based groups. MRC is currently recruiting representatives from additional states (see www.medicarerights.org/maincontentpolicytakeaction.html). Interested applicants must have Medicare and should e-mail CAB Director Isela Chavarria at chavarria@medicarerights.org or Policy Associate Andrea Kastin at akastin@medicarerights.org for additional information. Medicare Rights Center (MRC) is a national, not-for-profit consumer service organization working to ensure that older adults and people with disabilities receive high-quality, affordable health care. For more information about MRC, call (212) 204-6233, or visit the MRC web site: www.medicarerights.org.

MCR Answers Some FAQs About Medicare

Note: This article is based on questions addressed to "Dear Marci", an email service of the Medicare Rights Center (www.medicarerights.org).

Can a person enroll in both Medicare and Medicaid at the same time?

Yes, but enrollment cannot be done through the same form or at the same office. People with Medicare may be eligible for Medicaid if their income and assets are below a certain level. Medicaid is a federal program administered by each of the states, which offers health care coverage to people with low incomes and limited assets. Standards

for eligibility, benefits and amount, duration and scope of services, vary from state to state.

If you have both forms of insurance, Medicaid pays your health care provider after Medicare. In many states, having both Medicare and Medicaid means that you will not be responsible for paying Medicare premiums. You will also not have to pay deductibles and coinsurance if you use doctors who accept Medicaid. And you will have additional benefits, such as prescription drug coverage.

Different offices depending on the state that you live in administer enrollment for these programs. The Social Security Administration handles Medicare enrollment. To enroll in Medicaid, you generally must fill out an application at your local Medicaid office and provide documentation of your income, assets and other information.

For more information on how Medicare coordinates with Medicaid, visit the Medicare Rights Center's webpage on Coordinating Benefits.

The government's Medicaid website provides information on Medicaid as well as a list of state-by-state Medicaid Toll-Free "800" numbers.

Support for Video Description Restoration Act

ACB and other advocacy groups are trying to get the Chair and members of the House Committee on Energy and Commerce to sponsor our Video Description Restoration Act! (VDRA) If you know or know someone who can contact either Chairman Billy Tauzin (Phone 202-225-4031) or other members of the committee to urge the Chair to sponsor the proposed legislation, then please do so! Visit www.acb.org for a list of committee members.

The VDRA restores the Federal Communications Commission's (FCC) video description rules, recently overturned in Federal Court. The Act would guarantee TV access for people who are not able to either see or otherwise understand what is happening visually during a television program. The VDRA would expressly grant FCC authority to restore its minimum requirements, with increased access over time.

Video description is the use of narration during natural pauses in dialog to let a person not able to see the screen know what is happening. Imagine yourself watching television. While music plays in the background, a voice describes a van marked "express air and heat" pulling up to a building where a sign reads "National Security Council." Inside the building the man crawls through an air conditioning vent to a conference room and attaches a small microphone at the base of a vent above a table. The camera switches between people entering the room and the van pulling away from the building. There are countless scenes such as this which would leave a visually impaired person who can not see what is happening on the screen only to imagine what was happening and, further, frustrated by the lack of information.

Currently there is a residual amount of video description on television, made available from the time when the FCC mandate went into effect in April 2002. However, this described video is not secure; and even when it is broadcast by the networks, ACB's national membership reports that the pass through of description on satellite, cable, and local stations is spotty at best.

The FCC required the major networks and cable channels in the top twenty-five television markets to present at least four hours of described programming per week. The FCC further required that video described programs be made available where TV stations not in the top 25 markets had the equipment to do so.

The vast majority of the blindness community enjoyed and continues to want video description as a matter of access and fairness. In many ways, video description is for blind people what closed captioning is for those who are deaf. Because the infrastructure is already in place and has been since the FCC mandate, no major effort is required of the industry to continue the service. Modern television increasingly relies upon visual effects and scenes to convey important elements of the plot, in contrast to older programming that was more dialog oriented. Some networks such as Fox have been very supportive of the needs of blind and visually impaired viewers; they have even exceeded the requirements of the original mandate. But there are others who may well choose to drop the service; and even in those cases where networks continue to broadcast descriptions, the service is useless if it never makes it to consumers because of broken links in the delivery system which now has no responsibility to comply with an FCC rule now defunct.

The American Council of the Blind and all the other members of the National Television and Video Access Coalition have supported video description for more than 15 years. They understand that the service affords visually impaired people the same access to information on television that sighted viewers take for granted. Other groups and advocates, including The American Association of Retired Persons, The American Foundation for the Blind, The Blinded Veterans Association, The Washington Metropolitan Ear, and other disability and deafness groups have also supported the service for the same reason. The FCC order came only after the commercial industry had essentially ignored the access issues for those 15 years.

Video description is considered relatively inexpensive. Producers of the service currently charge between two and four thousand dollars for an hour of programming.

Consider yourself and your family. If anyone were to lose vision and reach a point where they need to have television described, would this not be best accomplished by a professional service that accompanies television programs? There is not always someone else around to describe what is happening visually in a given television program, and family members and friends may have varying tastes, amounts of free time, or preferences. Should a visually impaired person have to rely upon the generosity of others in a household to acquire such basic information when it has been adequately demonstrated that video description can be delivered easily and economically by the television networks? Also, consider that vision loss is a common occurrence with aging and video description is a way to guarantee that those who encounter vision loss will not be left out of the ability to enjoy television in much the same way they always did.

For ongoing information, visit the web site of the American Council of the Blind at www.acb.org or call 202-467-5081

Assistive Technology

Make it BIGGER **By Dawn Wilcox**

Windows provides some very useful ways to customize the screen without special software. For many people with impaired vision, including the present author, these tools provide enough size and contrast. My operating system is Microsoft Windows 98 and my web browser is Internet Explorer 6, but the various versions of Windows and Internet Explorer have essentially similar functions.

The following directions use built in features of Win98 and IE6 to enhance your monitor's visibility.

Control Panel:

The enhancements we will use in Windows are all in a program called Control Panel. There are at least two ways to get to the Control Panel:

1. On the desktop Highlight and enter or click on - My computer. Then, click on Control Panel.

Or

2. Press the Windows Logo Key to access the Start Menu. Press "s" until Settings is highlighted and then press Enter. Press Enter on Control Panel. You now have a List Box from which you will explore three options: Accessibility, Mouse and Display.

ACCESSIBILITY OPTIONS - This multi-page dialog box has 5 tab pages. Use control-tab or mouse to choose the third tab 'Display'; then that page opens.

DISPLAY - There is a check box for using high contrast choices. You can mark the box via the mouse, space bar or alt U (for use.) The button next to it is named 'settings'. If you click or use alt-S, 3 radio buttons appear for either 'white on black,' 'black on white' and 'custom'. You choose one of the radio buttons using the mouse, space bar or alt plus W, B, or C. If you choose C (custom), the combo box showing all the possible choices of color and size combination is live and you can go down the choices with an arrow, or mouse. It looks like the same list you get from control panel/display/scheme. *See below. There is also a keyboard shortcut at the top of this page; if you check this, you could have one basic mode and just do the short cut when you wanted high contrast. After you make these choices, you have to click the ok button. You can always return and change things back. Since people with low vision have such a varied range of preferences of size of text, contrast, color etc., so you need to try out different choices to see which works best for you--the object being visual efficiency and comfort.

MOUSE - From the control panel click on mouse. Here is another set of tabs and choices called Mouse Properties.

Go to Pointers If you go to 'scheme' on the pointer page, you can make the mouse pointer different sizes. There is also an inverted mouse pointer which changes its color depending on the background. There are a lot more changes you can make on the other tab pages.

DISPLAY - This dialog box has 6 tab pages; choose 'appearance.' Tab to 'scheme'; go down with arrow key to see what each one does as it shows on screen. There are many choices here from eggplant to high contrast and windows standard which have a choice of size. Choose one and tab to 'save'; you can name this now or use the default name, then click or enter. At this point you can click/enter or 'ok' at the bottom of the page and see how your favorite pages look, or continue.

Tab to the items list. Down arrow to desktop, menu, inactive window etc. Tab to size to change font for just that item. Tab to color to change color for just that item. Tab to 'ok' and click to save all these choices. Use your word processor etc. to see what you've created. Return to 'display' to adjust things. Be sure to name your final product so you will be able to get it back if you or someone else decides to try out new choices.

INTERNET EXPLORER via IE/view/text

You can choose large text size on the WorldWide Web via Internet Explorer: Press alt key, then 'v' for the view menu pulldown. Type 'x' or arrow down to text size. Another menu appears with a bullet in front of the choice; arrow up or down or type the

underlined letter: Largest 'g', Large 'l', medium 'm', smaller 's'. Enter and the change is made. Be careful with largest - the whole web page may not be on screen, which is a problem if you try to print it.

Pulse Data and Benetech Announce Collaboration to Make Books Accessible

Pulse Data International, the world's leading manufacturer of products designed for people who are blind and visually impaired, and Benetech, the Silicon Valley technology nonprofit formerly known as Arkenstone, announced a formal collaboration integrating Benetech's Bookshare.org initiative with Pulse Data's BrailleNote family of products. Bookshare.org is a subscription service that provides an extensive online library of accessible digital books to U.S. residents with severe visual, reading and mobility disabilities. The BrailleNote Family is the first suite of Personal Data Assistants designed for people who are blind. Since last September, the Windows-CE based KeyWeb Internet Browser has been integrated into the entire range of BrailleNote products.

This collaboration allows BrailleNote users with a Bookshare.org subscription to browse the Bookshare.org website using the BrailleNote, select one of the 12,000 books already available from this site and download it directly to the device. The user can then press enter on the downloaded book, and will be prompted for his Bookshare.org user name and password. The BrailleNote will then seamlessly unpack the downloaded book to the BrailleNote's bookreader to be read off-line. This unpacking scheme preserves the book's copyright protection.

This functionality was debuted by Pulse Data HumanWare CEO Jim Halliday on February 21 at the Vision Loss In the 21st Century Conference, which is sponsored by the American Foundation For the Blind. In his speech, Halliday stated, "Because of this new development by Pulse Data International and the tremendous service Benetech is providing with its Bookshare.org project, BrailleNote users can now have 12,000 Braille books available to them instantly. This is a long time dream come true for Braille readers." Jim Fruchterman, founder and CEO of Benetech, said, "Lowering barriers to book access is the core objective of Bookshare.org. By building access to our collection directly into a device like the BrailleNote, we make it possible for a blind person to carry around their own personal library in Braille!"

"This effort further illustrates Pulse Data's commitment to promote Braille literacy via portable, independent, seamless acquisition of electronic text by persons who are blind," states Larry Lewis, Product Marketing Manager for the BrailleNote. And Bookshare.org Senior Product Manager Alison Lingane notes, "Our goal is to make access to the wide collection of books from Bookshare.org as seamless as possible for our members. This collaboration is a dramatic move to support Braille readers."

In celebration of the partnership, Pulse Data HumanWare is offering a \$100 discount to all Bookshare.org subscribers who purchase a BrailleNote or a VoiceNote, while Benetech is offering new Bookshare.org members who purchase a new BrailleNote/VoiceNote or upgrade \$25 off the purchase of an annual subscription to Bookshare.org's rapidly growing collection of accessible digital books. Contact Pulse Data at 888-886-3282, Benetech at 877-282-3522, and Bookshare at www.Bookshare.org

Designs for Vision's New Metal Frame Available at Lighthouse Store

Lighthouse International offers the cosmetically appealing -- and strong -- "Onguard" metal frame from Designs for Vision. The frame, which comes in gold and tortoise, is available for spectacle-mounted telescopes in the Designs for Vision line. When considering your next bioptic telescope, ask about the new 047 DV metal "Onguard" frame by E-mailing superstore@lighthouse.org or calling (800) 826-4200. Ask for a free copy of the latest professional products catalog offering a large selection of low vision optical products.

Amazon.com Launches Accessible Website

Amazon.com launched an alternative version of its Web site, called "Amazon Access," that is designed to make online shopping easier for customers who use screen access software. Screen access software, which reads aloud text and links, is one of the main tools used by the visually impaired to tap the Internet. Amazon's new Web site is basically a streamlined version of its standard site, with less text and graphics. "We created the site for our visually impaired customers so it would be easier for them to navigate," said Robert Frederick, manager of Amazon Anywhere. Amazon has maintained a text-only mode of its standard e-commerce site since it first went online in 1995. However, many customers still were having trouble, according to Frederick. "A number of Amazon's customers had either e-mailed us or contacted customer service about the problems they were having," he said. In response, the company created a specially tailored site to meet their needs. "We wanted to make sure all of our customers had the best shopping experience possible," Frederick said. The address for the web site is: [>>http://www.amazon.com/access](http://www.amazon.com/access)

People

Careers Officers Told Me It Was Ridiculous to Consider the Stage and Suggested I Become a Typist **By Beverley Kemp**

Reprinted with permission from The Times (London)

Karina Jones was 13 when she realized she could no longer read what was written on the blackboard in class. At first her teachers didn't believe her when she explained that it was becoming harder to see, and suspected it was an excuse to get out of working. Only when Karina could no longer read normal-sized print did people realize she was telling the truth.

After a series of hospital tests she was diagnosed with retinitis pigmentosa. The condition covers a group of disorders of the retina which result in a progressive loss of vision and can develop in childhood or adulthood. First recognized in the 1850s, it was initially thought to be a rare condition. Today an estimated 25,000 people in the UK are affected. Now, at 31, Karina has peripheral vision but cannot see detail. She can see people approaching in the street but not their faces. And she has made a successful career as an actress. It is an ambition she had from an early age, even as her vision was deteriorating. "School careers officers told me it was ridiculous to consider a career on the stage and suggested I become a typist or telephonist," she recalls. "One of them

sat me down and explained that I needed a 'special job for a special girl', which sounded pathetic and just made me all the more determined."

So began Karina's battle to realize her dreams. With the help of her parents and friends, who transferred study material on to cassettes, Karina passed three A levels and graduated from Liverpool University with a degree in English and drama. Finding a place at drama school was not easy. "Although I had lots of auditions, most of them were reluctant to consider a student with any disability," explains Karina. Eventually she was offered a place at Drama Studio London in Ealing. "Other students later admitted that they thought I'd hold them back. But as time went on it became clear that, although I did things in a different way, I still managed to do everything everyone else did."

Karina learns her lines as quickly as sighted actors, using tapes or computer-enhanced large print. Despite this, on leaving drama school in 1995 it was an uphill struggle to persuade casting directors that a partially sighted actress could offer as much as a sighted one. "After my first audition I was offered the part," she says. "I was over the moon. But as soon as I asked for the script to get it on to tape the director was obviously horror-struck. He mumbled something about getting back to me - I never heard from him again."

Agents declined to represent her on the grounds that it wouldn't be profitable, so Karina began applying for roles advertised in *The Stage* and other trade magazines. She also adopted a desperate strategy in order to get work.

"After being turned down for a few parts I felt I had no option but to be less than honest when I went for an audition," she explains. "Instead of saying I was visually impaired I began telling casting directors that I was dyslexic or short-sighted." Offers came in, but they brought new stresses. "I'd get the job, then other cast members would smile or wave at me from across the room and I wouldn't see them. It didn't make for good relations with the rest of the company. Knowing I was trying to hide my impairment made me feel really down." One day she read an interview with David Blunkett, then Secretary of State for Education, where he talked about how difficult his blindness had been for him when he was starting out on a career. Karina wrote to him explaining about the prejudice she was facing. He sent a sympathetic reply on tape offering encouragement. "Knowing someone else had been through it and had become successful made me feel much more positive," recalls Karina.

She decided she could no longer keep up the pretence of being dyslexic and reverted to being upfront at auditions. By now actors she'd worked with had started recommending her for jobs. Within months offers were coming in. In the past five years Karina has played leading parts in national productions, including *The Fly*, *The Changeling*, *A Christmas Carol* and a one-woman show called *Resolution*. She was nominated for Best Actress in the Manchester Evening News Awards for her portrayal of a blind woman in *Crystal Clear* at the Lowry Theatre in Manchester - the only visually impaired part she has played. When the Queen and Duke of Edinburgh came to open the Lowry the Duke, in customary diplomatic mode, said to Karina, "Careful you don't fall off the stage!" "It didn't offend me at all," laughs Karina. "I could see the funny side."

Her career continues to be successful but the challenges facing Karina are far from over. "Most other actors have role models they admire," she explains. "Black actors may aspire to be the next Denzel Washington. But there are no well-known disabled actors. Even those playing disabled parts in dramas and soaps are able-bodied in real life. People still worry you might trip over."

Her ambition now is to break into television. "It won't be easy, but my disability drives me on because sometimes I get so annoyed it pushes me to do the best I can. I wouldn't be happy doing anything else."

Request for Contributions

CCLVI gratefully accepts contributions from readers and members to help pay for the costs of publishing VISION ACCESS, the costs related to our 800 line and Project Insight, and for funding the Carl E. Foley and Fred Scheigert Scholarships. Please send contributions to CCLVI Treasurer, Coletta Davis 2879 East Alden Place, Anaheim, CA 92806. Our Tax ID number is 1317540.

Resources

ACVREP (Academy for Certification of Vision Rehabilitation and Education Professionals)

Sharon L. Milkrot, President
4633 N. 1st Ave
Tucson AZ 85718
(520) 887-6816
e-mail: smilkrot@acvrep.org

Amazon.com

<http://www.amazon.com/access>

American Council of the Blind

(202)-467-5081
(800) 424-8666

Benetech

877-282-3522v
www.Bookshare.org

CCLVI

1155 15 Street, NW
Suite 1004
Washington, D.C. 20005
800-733-2258

CCLVI Treasurer

Coletta Davis
2879 East Alden Place
Anaheim, CA 92806

CCLVI Chapters

California Council
800-733-2258

Delaware Valley Council

215-835-5888

Florida Council
800-267-4448

Metropolitan Council
845-986-2955

National Capitol Council
ncclv@yahoo.com

Charles Gourgey's Website
<http://www.judeochristianity.org/>,

Columbia University Study
Amy Lowenstein, AEL2004@columbia.edu, Tel. (917) 975-1186

House Committee on Energy and Commerce, Chairman Senator Billy Tauzin
2183 Rayburn House Office Building
Washington D.C. 20515-1803
202-225-4031

Internal Revenue Service
(800) 829-4059
IRS publications: Tax Topic 101, Publication 910 and Publication 907. Call
the local IRS Taxpayer Advocate office at (504) 558-3001.

Dr. Randy Jose:
rjose@uh.edu www.biopticdriving.org.uk
Randall Jose, OD, FAAO,
Head of Program Committee, Director, Center for Sight
Enhancement/University Eye Institute,
University of Houston/College of Optometry,
505 J. Davis Armistead Bldg. Houston, TX 77204-2020 USA 713 743 0799 F:
713 743 0190

Lighthouse
superstore@lighthouse.org
(800) 826-4200

Medicare Rights Center, MRC
(212) 204-6233,
www.medicarerights.org.
(
MRC Consumer Advisory Board
CAB Director Isela Chavarria
ichavarria@medicarerights.org
Policy Associate Andrea Kestin
akestin@medicarerights.org

National Library Service for the Blind and Physically Handicapped
Library of Congress
1291 Taylor St., Northwest, Washington, D.C. 20542.

National Vision Rehabilitation Cooperative
www.Meicarenow.org

Jane Pic
P.O. Box 9062
Metairie, LA 70055
jpicad@msn.com

Pulse Data
888-886-3282

wgps listserv
<http://groups.yahoo.com/group/wgps>

CCLVI 2003 Membership Application or Renewal

Please send dues payment to CCLVI Treasurer, Coletta Davis
2879 East Alden Place, Anaheim, CA 92806

Name _____ M F _____
Address _____ City _____
State _____ Postal Code _____ Country _____
Phone _____ E-Mail _____

_____ New member.
_____ Life or paid up Life member in year(s).
_____ Organization or Agency.
_____ Person with low vision.
_____ Totally blind person. _____ Fully sighted person.

I wish to receive the Vision Access in the following format:
_____ Large print _____ Cassette _____ E-mail _____
Do not send Vision Access

I wish to receive the Braille Forum in the following format:
_____ Cassette _____ Large Print _____ Braille _____ E-mail
_____ Computer Disk _____ Do Not Send Braille Forum

Please indicate your local CCLV chapter preference:
_____ California _____ Florida _____ Delaware Valley
_____ National Capitol _____ Metro (NY/NJ)
_____ Member At Large _____ Do not inform local chapter.

Please Include a Dues Check for one of the following:
_____ US or International Individual \$15.00;
_____ Organization or Agency \$25.00
_____ Life Member \$300.00. *May pay in three (3) annual installments of \$100.00.