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Vision Access welcomes submissions from people with low vision, from professionals such as ophthalmologists, optometrists, low vision specialists, and everyone with something substantive to contribute to the ongoing discussion of low vision and all of its ramifications.

Submissions are best made as attachments to email. Submissions may also be made in clear typescript. VISION ACCESS cannot assume responsibility for lost manuscripts. Deadlines for submissions are March 1, June 1, September 1, and December 1. Submissions may be mailed to Joyce Kleiber, Editor, 6 Hillside Rd., Wayne, PA 19087, jmkleiber@hotmail.com

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Sarah Peterson
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Mike Vogl
Running Cross Country Despite Stargardt’s Disease, Summarized by Michael Vogl

Quality of Life

Beep Ball, College Prep, and Scott MacIntyre: A Glimpse of the Summer Camps That Changed My Life, By Sarah Peterson

Vision Impaired Need More Accessible Materials

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CCLVI Officers and Board Members

CCLVI Chapters
From the Editor

Were you surprised when you opened the large print version of Vision Access? In this edition, we are attempting to phase in the recommendations of CCLVI’s Large Print Committee. This committee, headed by Tom Lealos, worked diligently for two years to develop a document entitled “Best Practice Guidelines for Use with Large Print.”

So in addition to the 18 pt. bold Verdana font which we introduced in the Fall, 2011 edition, we have increased the space between lines from single to 1.5 space. Then we’ve added a line between paragraphs.

In this magazine read Richard Rueda’s article entitled “Best Practices Guidelines for Use with Large Print,” and then go to www.CCLVI.org to read the document prepared
by our Large Print Committee. Let us know what you think about these changes. Call us at 800-733-2258 or email to the editor, jmkleiber@hotmail.com. Please put “Vision Access” in the subject line of your email message.

Thanks to everyone who contributed articles and ideas to this issue of Vision Access. Happy New Year! JMK, 12/9/2011.

Organization News

President’s Message, By Richard Rueda

As 2011 collides into 2012, we pause and give thanks to another year of health and good cheer. CCLVI continues to provide its members with opportunities to assist the organization in moving forward. In 2012 we will see quite
a few changes to the face of our organization. Namely this summer many of our current board members will either term out and or move onward to pursue new adventures in their lives. Others who have chaired our committees will also be stepping down from leadership posts to spend more time with family, work and personal projects that they selflessly postponed to serve CCLVI.

This is where you our members come in. CCLVI, like many affiliates in ACB and local state councils and chapters is eager to be the best it can with limited but meaningful resources. Often people ask me what it’s like to be in a leadership role and help move along an organization. And quite honestly my reply is “It’s what you make of it.” And if enough people pitch in and remain focused
and determined, a lot of great work can be done. The challenge comes with not only finding the right person for the right job, but also prioritizing what the committee and organization as a whole can truly accomplish and then do it with pride. The last thing here is for each volunteer to only accept a small amount of volunteer jobs in any given organization. The challenge is to find the courage to say "no" when you are feeling that you are at the tipping point and to find others in your circle, who share likeminded values and can and are willing to pitch in.

With that, I want to strongly urge our members, readers and other interested individuals to take what I am posting here to heart. Challenge yourselves in 2012 to become engaged in CCLVI.
Take the torch and carry with pride our values and beliefs that people with low vision can and should be active participants in the worldwide community.

I am President of this organization through mid-July. I want you to know that together we can do great things. Please call upon me to help you see what you can do. I hope to hear from all of you who read this and consult with you to determine where your passion can be matched with CCLVI's offerings. My phone number is 510.825.4106. Or email to richardrueda@sbcglobal.net.

Best Practice Guidelines for Use with Large Print
By Richard Rueda
Editor’s Note: Richard Rueda, CCLVI President, addressed the following comments to ACB leaders, friends and colleagues.

For nearly two years now the Council of Citizens with Low Vision International (CCLVI) Large Print Committee has been working on best practice guidelines for use with large print document creation and distribution. By now some of you may have received a copy of these guidelines in the mail or had reviewed them during our conference in Reno this past July.

Recently we put these guidelines up on CCLVI's web page and invite you and your colleagues and other professionals working in the field of low vision to review and share this well thought out document with others. This document features researched
Requests from Convention Planning Committee
By Lisa Drzewucki

I know it probably seems like this year's convention just ended, but it's already time to start thinking about next year. The current committee, which is comprised of myself, Richard Rueda, and Kathy Casey, met by phone to begin planning and we have...
two questions for you all:

1. Several people expressed an interest in joining the committee. I will be reaching out to them, but would love to hear from anyone else who might like to get involved.

2. What would you like to see, in terms of programming and events, at next year’s convention? Please let us know, and feel free to give us constructive feedback about last year. Email me at lisadrzewucki@aol.com.

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**Chapters Report on Advocacy**

**Metropolitan Council of Low Vision Individuals**

"Looking Good Looking Close"

In November, the Metro Chapter was invited by the Manhattan Borough President's Office to participate in "Transportation 2030." At this one-day conference about 450 community leaders, elected
officials and advocates discussed the future of all modes of local transportation including walking, paratransit and public transit.

Chapter President Ken Stewart was a member of one of the presenting panels. This panel included the City Department of Transportation's point man on the recent celebrated redesign of one midtown Manhattan intersection which received accessible pedestrian signals and detectable warning strips at all four corners and on median strips too!

The Metro Chapter continues to be an active member of the coalition of blind, vision impaired, and seniors' groups comprising "PASS", Pedestrians for Accessible and Safe Streets. That now very accessible Manhattan intersection is certainly a giant feather in PASS's cap.

Lighting Advocacy at Work within NCCLV

National Capital Citizens with Low Vision members and friends have noticed a major decline recently in the lighting in Metrorail stations in the Washington, DC metro area. In
response, we have formed a Lighting Committee. The members of this committee are very passionate about this topic! We’ve been busy advocating for our need to traverse safely and efficiently throughout the rail system.

We were invited to present our case at the Washington Metropolitan Area Transit Authority (WMATA) Bus/Rail Subcommittee of the Accessibility Advisory Committee meeting on November 14, 2011. (Now, isn’t that a mouthful?) During this meeting, we identified:

- Stations with major lighting issues that impact customers with low vision
- Lighting issues
- Consequences of poor lighting for customers with low vision
- Possible solutions
- Provided testimonials by Metrorail users with low vision

WMATA was impressed with our detailed reports and willingness to establish a partnership with them regarding issues related to low vision. This will be our strategy going forward. Our committee is excited and hopeful that we can create sustainable change. We’ve
already seen some improvement in the lighting! We’ve been invited back to the next Subcommittee meeting on December 12th where these issues will be discussed with lighting personnel at WMATA.

This advocacy work has also attracted people to NCCLV. The Lighting Committee encourages the chapters, CCLVI and all readers of Vision Access to advocate!

What are YOU passionate about? Get involved. Don’t wait for someone else to fix your problem.

To learn more about NCCLV, contact Barbara Milleville, President, at ncclv@yahoo.com or 703-645-8716.

Let’s Talk Low Vision Teleconference Schedule

Join us for the following teleconferences with Dr. Bill Takeshita by calling 218-339-2699, ID# 764516 at 5:30pm Pacific time, 8:30pm Eastern time.

January 17, 2012
The I Phone 4s with Siri: Is this the most
| Question: What do you do when someone is offering assistance, but is patronizing? This happens far too often. I was at a doctor's office. A nurse was taking me back to the waiting room for the pre-appointment workup. She talked to me as if I wasn't an adult on equal footing with her. Does your visual disability sometimes get misinterpreted as a lack of maturity or a lack of intelligence? Are you sometimes "talked down | What Reader's Want To Know

By Valerie Ries-Lerman

<table>
<thead>
<tr>
<th>What are telescopic glasses and who will benefit?</th>
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<tbody>
<tr>
<td>What’s new in video magnifiers?</td>
</tr>
</tbody>
</table>

February 21, 2012
The best advice for dating with low vision

March 20, 2012
accessible cell phone for the visually impaired?
How do you deal with this in an effective manner?

I'm afraid my feather's get ruffled and I don't handle these situations very well.

Are there any ideas out there for a quick comeback that's friendly but to the point? Please email your response or comments to: sacramentovalerie@yahoo.com.

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Science and Health

Preventing Infections During Eye Injections

Reported by Betty Pannell

In a study reported by Reuters Health August 11, 2011, researchers found that in just a few minutes of talking over an imaginary patient, unmasked volunteers representing doctors spewed out bacteria which could potentially land on eyes or injection needles and cause
infection. Some of these infections are caused by a type of bacterium, *Streptococcus*, that's common in the mouth.

Although the new finding "doesn't prove anything conclusively," said study author Dr. Colin McCannel, from the Jules Stein Eye Institute at the University of California, Los Angeles, "my advice to patients would be, until the injection is complete ... minimize conversation or talking with the physician."

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Make a Plan to Manage Diabetes and Prevent Complications

Many people with diabetes can avoid long-term problems by setting goals for their health and taking steps to manage their diabetes.

Visit the “Make a Plan” section of the
People

Running Cross Country Despite Stargardt’s Disease
Summarized by Michael Vogl

Editor’s Note: This article is a summary of a report from TODAY.com by Lisa A. Flam, a TODAY.com contributor. [http://today.msnbc.msn.com/id/45034031/](http://today.msnbc.msn.com/id/45034031/)
Sami Stoner is running proof that adversity doesn’t have to keep you from the finish line. A legally blind 16-year-old runner, Sami is traversing cross-country courses with her new guide dog, Chloe, and is believed to be the first high school athlete in her home state of Ohio to compete with an animal.

“I don’t run for time or place or anything, I just run because I love it, and I’m glad I can share my love of running with Chloe now,” says Sami, a junior at Lexington High School who’s on the junior varsity cross country team.

Sami won a waiver from the state high school athletic association that allows her to compete with a dog. The golden retriever, who guides Sami through the crowded hallways at school, also takes her safely through the running trails. “She watches out and picks the clearest path for me,” Sami says cheerfully. “The ways she moves, I can feel it in her harness, so she has little ways to signal which way to go and what to do.”

Sami and Chloe are usually passing other competitors by the first mile on the 5-kilometer (3.1-mile) course. Sami is
ineligible to score, and she must avoid finish-line chutes if they’re deemed too narrow.

Running with just some peripheral vision is scary, Sami says. But Chloe is highly focused, and helps Sami feel secure enough to improve her personal record to 29:53.

“There is still a little element of being terrified you’re going to fall flat on your face,” Sami says. “She’s given me a lot more confidence in my running.”

“It’s an amazing, scary thing to see her take off and all you can do is pray that everybody comes back safely. This is my baby,” says Sami's dad, Keith. “She’s not necessarily up there collecting a medal at end of the race, but in our heart she does win them all.”

Sami began running cross-country in eighth grade, and by the end of that school year, her vision deteriorated and she became legally blind with untreatable Stargardt’s disease.

In high school, she first teamed up with a friend, Hannah Ticoras, who ran alongside her as a guide. “All I wanted to do was run, and running with Hannah gave me that
opportunity,” says Sami. When Hannah graduated, Sami had the opportunity to get a guide dog to help her carry on her dream.

“I just hope people learn that just because you have a disability or some kind of disadvantage that it’s not the end of the world,” says Sami, who has a 4.0 grade point average this year. “You can still do stuff, you just have to find a way of doing it.”

Quality of Life

Beep Ball, College Prep, and Scott MacIntyre: A Glimpse of the Summer Camps That Changed My Life, By Sarah Peterson

Loneliness and low self-esteem are seemingly two of the most common feelings experienced during the turbulence of adolescence, when the yearning for acceptance
is perhaps the most fervent. I think most would agree that the tender teenage years are often accompanied by the individual’s desire to know that he or she is not alone in the struggle to find one’s self and, once discovered, embrace it wholeheartedly. I also think this battle might be more difficult for those confronting a unique situation, specifically an impairment of some kind. The sting of such a predicament is probably the worst during a period defined by the fight to be “normal.”

As the only visually impaired student in my small Kansas community, I certainly did not successfully master the art of “blending in.” Throughout my childhood, I consistently encountered bantering about my glasses with their substantially thick lenses and stares as my orientation and mobility instructor gave me
white cane training on school grounds.

For quite some time, I sincerely began to assume that I would never meet anyone who understood. But beginning at age twelve, I received one opportunity after another to learn that I was mistaken. Three very special, very unique camps I eventually attended equipped me with the confidence to face my disability head-on and perceive it as something beautiful, as well as the pride to share my story with others. The experiences I enjoyed at these camps and the lifelong friendships I discovered there were genuine blessings that enabled me to not simply survive the most difficult period of my development, but also to flourish.

My very first camp adventure occurred when I was twelve years old. I had never attended a summer camp before, likely since
the great outdoors is not always a comforting environment for a child who cannot see everything around her. I had always listened enviously as other children spoke of staying in cabins, spending entire summer days at the lake, enjoying nightly campfires munching on s’mores, and simply discovering all the joys nature has to offer, greatly saddened that I possessed no similar exciting experiences to share. One day during the sixth grade, a close friend described a summer camp her eye doctor had told her about, a camp exclusively for youth with low vision. I had no clue such a wonderful thing existed! Heather’s Camp, established in 2001 and based out of Rock Springs near Junction City, Kansas, was created to honor the memory of Heather Muller, a woman passionate about helping children with special needs who had
been tragically killed in a homicide years earlier. Made possible by the Envision Rehabilitation Center, Via Christi Hospital, and women of Wichita State University’s chapter of Delta Gamma Fraternity (an organization of which Heather had been an active member), Heather’s Camp provides a safe, fun place where children with visual impairments can enjoy the full summer camp experience. After speaking with my parents, we filled out the paperwork, and on an early August morning, I embarked on a three-day adventure filled with canoeing, archery, arts and crafts, beep ball, hiking, horseback riding, campfires, swimming, dancing, and making friends, surrounded by some of the most precious individuals I had ever met. Those three days marked the beginning of an eight-year involvement with Heather’s Camp, which eventually transformed
my role from camper status to counselor. I now look forward to returning each summer I am able to assist as a counselor, or serve in whatever helpful capacity I can so that a child’s dream can come true.

Heather’s Camp, in its effort to bring together now nearly seventy or eighty Kansas youth with visual impairments, has taught me that I am certainly not the only one who possesses the burdens of these circumstances. Eight years later, I possess more confidence in nature and anticipate many more years to come with the many friendships that developed during those sultry summer days.

Of course, while no one should grow too old for things such as campfire songs and romps in the outdoors, I was in need of some additional skills that would prepare me for a summer job and
eventually college. My opportunity to obtain such knowledge arose with a suggestion from my teacher of the visually impaired. She informed me about a Kansas State School for the Blind outreach program called VIEWS, which stands for Visually Impaired Experience Work Success. VIEWS provided small groups of Kansas teens with low vision an entire week of fun and learning, equipping them with confidence and skills needed to return to summer jobs the Kansas State School for the Blind set up for each of them back in their hometowns. The activities also offered a taste of college life, encouraging the students to consider post-secondary plans.

In July, I joined a small group of teens with visual impairments at a low and high ropes course at a campground near Lawrence, Kansas. After spending an afternoon of getting to
know each other and teambuilding activities, we spent the night in comfortable cabins and embarked on our adventure of spending an entire week on the campus of Emporia State University. Staying in the dorms and dining in the cafeteria, we attended several engaging workshops that taught us about college, the workplace, and how to advocate for ourselves in each. One even prepared us for the mock interview that eventually culminated the week. Other activities included an orientation and mobility scavenger hunt in the mall, a day trip to a vision rehabilitation center in Topeka, and multiple game nights with plenty of time to become better acquainted with my fellow campers.

During the following weeks of summer after my return home, I worked daily at my hometown’s Jordaan Memorial Library, a
milestone for which the VIEWS program helped to prepare me. I spent the remainder of the summer totally in my element, completely surrounded by books and assisting patrons obtain as much as possible with what our library has to offer. After a day or two in orientation with my VIEWS outreach coordinator, I possessed the full confidence needed for my summer job. The VIEWS program, which unfortunately has terminated due to lack of funding, offered me an opportunity to return the following summer as a mentor for their other campers. To this day, I consistently utilize the skills with which VIEWS has equipped me and I continue to keep in touch with the charming, courageous individuals that I befriended there.

As I awaited my rapidly approaching high school graduation and purchased my own laptop computer, my
teacher for the visually impaired reminded me that I needed to enhance my technology skills for college. With this in mind, she informed me of Envision’s Assistive Technology Camp for teens with low vision that occurred every summer. After briefly considering her suggestion, I planned to attend yet another camp and a week full of wonderful memory making. Envision’s AT Camp was jam-packed full of exciting, fun things to do and learn. We spent four hours each afternoon at either the Wichita State University or Envision computer labs learning about the laptop computers each of us received and how to utilize System Access, a keyboard shortcut program with voice created especially for individuals with low vision. All campers were paired with mentors, people familiar with this technology who could assist us whenever we needed
help. Throughout the week, we learned all about System Access and how to memorize the many keyboard commands, sharpened our Internet skills, and explored programs such as PowerPoint and Excel. We spent the majority of the time enriching our word processing skills by composing individual resumes, job applications, and cover letters. At the end of the week, each camper composed a portfolio that included each of these items and participated in a mock interview, which helped us to know what to expect when applying for a real job. Following our efforts, we were all treated to a professional business luncheon at the Petroleum Club accompanied by the CEO of Envision. Outside of the lab, we spent our mornings touring various businesses around Wichita and chatting with their employees. Evenings were filled with fun activities such as
bowling, board games, and general socialization. Favorite memories of the campers always included the inspiring discussions we enjoyed with various individuals, whether it was a successful employee with low vision at a bank, the coordinator of WSU’s student disability services, or a phone conference with 2009 American Idol finalist Scott MacIntyre. Like Heather’s Camp and VIEWS, I was blessed with being requested to return as a mentor the following summer.

Entering college, I credited much of my success and confidence to AT Camp and all the skills it provided me with, not to mention the many inspiring individuals who made an impact on my life.

I am now fully beginning to realize how very blessed I am, having received the opportunity to attend camps, one after another, for visually impaired youth. I
sincerely feel that each was a response to the cry in my heart and an answer to my prayers. The camaraderie I encountered at each equipped me with the confidence and strength to both persevere and thrive as a low-sighted individual in a highly seeing world. Once I conquered the first (and most difficult) task of all, simply being open about my vision and accepting the risk to ask questions, my loneliness quickly diminished as I received more and more opportunities to gather with people understanding of my situation. I also walked away with pride, a joyful heart-swelling sensation when I recall that my low vision associates me with some of the most beautiful, courageous people I know. I now realize that my task is to encourage people to openly discuss their vision and actively seek the rewarding situations it can create. While I seemingly stumbled across my camps, I know that sometimes
only the best of opportunities must be consistently searched for with perseverance. Counseling and mentoring were also milestones to which I did not even dream these camps would lead me.

Because I accepted these offers, I realize that a large part of my calling is to advocate for individuals with low vision, especially youth, whenever possible. Unfortunately, as I have learned the hard way, camps like Heather’s Camp, VIEWS, and Assistive Technology Camp are only made possible through creativity, effort, and funding. I plead with all people to never dismiss big ideas, as crazy or as unrealistic as they may seem, especially if they can lead to changing lives. Despite the tough economic situation, we must also work to raise awareness to our state and federal governments of the dire need for funding for these programs. I hate
to think of the hundreds of teens who could not have been helped by VIEWS simply because of a lack of money. While the camps provided me with necessary skills and lifelong friendships, they have also enabled me to embrace myself and my circumstances, reminding me that I am never alone in my trials and always have a reason to rejoice.

**Vision Impaired Need More Accessible Materials**

Editor’s Note: This information was reported in the Pennsylvania Council of the Blind Listserv.

A new U.S. Department of Education report dated 12/9/2011 addresses course material accessibility for students with disabilities. It calls for establishment of a process to create
uniform accessibility industry guidelines and emphasizes the importance of compliance with civil-rights laws for institutions of higher education.

The 175-page report, from the Advisory Commission on Accessible Instructional Materials in Postsecondary Education for Students with Disabilities, took more than a year to write and was mandated by the Higher Education Opportunity Act of 2008. It offers numerous findings and calls to action in the areas of legal and policy, market solutions, technology, institution capacity building, and demonstration projects.

“Commission members agree that a potentially viable accessible digital marketplace is emerging in some areas, but there is not agreement that this progress is occurring within all components of the
instructional materials enterprise,” the report said. “While textbook publishers and a number of e-text vendors are moving to incorporate accessibility into their products, some developers of web applications, social media and productivity software used to support postsecondary instructional practice are less proactive.” Here is a direct link to download the report http://dl.dropbox.com/u/5975417/aim-report.doc

Connecting with an Appropriate Mental Health
As we go through life, we may benefit from professional counseling. Finding a mental health professional with whom we want to work can be a complex process for anyone; but there is even more to consider when we have low vision.

Initially we will want to ensure that our therapist is covered by our insurance or has a sliding fee scale or can accept our payments. Then we will want to know whether our therapist has sufficient training to address our
needs, whether these be individual, family, or marriage/couples counseling, sexual abuse, trauma, and others. Is our therapist culturally competent in compliance with his or her regulating mandates from professional codes? Then we will want to consider “How do I, a person with low vision, connect with my therapist?”

Beyond what they learned in their educational settings, therapists may have had little or no experience in working with people with disabilities in general and with people who have low vision specifically. They may be functioning with archaic beliefs about what we have experienced and what we are capable of accomplishing. We may well be their educators in this regard. Our low vision may evoke feelings of vulnerability in our therapist. We may have to explain to our therapist what it is
like to have low vision. We can help our therapist to understand our world.

Then we may simply need to be assertive and state what we believe is the problem. Here are some examples: “I’m depressed,” “I’m anxious and worry all the time,” “I am having difficulties with my family who try to hold me back,” “My husband and I have communication problems,” “I am having difficulties with socializing/dating.”

Some mental health concerns may result directly from having low vision. Having low vision can have emotional challenges and counseling can help to address these. We may be depressed or anxious because of our low vision. Loss issues related to our disability should be explored. These losses may include loss of vision, changes in our perception of what we can do, the need to
modify our life, changes in responses of our family and friends, and many others. Our hopes and aspirations may need to be modified; income and security may be threatened; our position in the family and social structure may be altered, and feelings of helplessness and weakness may replace a former sense of strength and competence. It is essential that we be permitted to experience and grieve these losses and be assisted through the grief process.

Family counseling may be helpful because members of our families often go through an adjustment phase as well and may be experiencing stress because a member of their family has a disability.

In a therapy session we may not be able to make eye contact or read the facial expressions of our therapists. It may be important to tell our therapists that we have
this limitation. Good therapists will compensate for this by using words to convey feeling and other responses. Our difficulty in reading emotions portrayed by facial expressions may pose problems in family counseling session where many people may be communicating nonverbally. But astute therapists will describe the nonverbal communication that occurs so that we will be included in the dynamics of the session.

There can be other reasons apart from our low vision for feeling depressed, anxious or for having relationship problems. These, too, deserve professional attention.

Connecting with a professional is much like any other connection with people—some people relate well to one another, some simply do not. When a connection is not made, it may be no fault of
ours or of the therapist. When this happens, we can talk openly with our therapist about this. Perhaps this problem can be resolved by addressing transference or countertransference issues, communication problems, and differences in expectations. If no resolution is reached, then perhaps a referral to another professional will be necessary. When the problem is discussed and resolved, we can focus on our healing which is the purpose of seeking mental health treatment.

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, Mike Godino, 104 Tilrose Avenue, Malverne, NY 11565-2040. Our Tax ID number is 1317540.

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**Resources**

Convention Planning Committee  
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Dept. of Education Report  

Managing Diabetes  
www.yourDiabetesInfo.org  
888-693-6337

Readers Want to Know  
sacramentovalerie@yahoocom
Council of Citizens with Low Vision
International, An Affiliate of the American
Council of the Blind
2012 Membership Application

Name____________________________________________________
Address_____________________________________________________________________
City_________________________ State _______ Zip Code ___
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Membership Status: I am:
___ New member. _____ Life member of CCLVI.
___ Renewing my membership.
___ Life member of ACB.

Visual Status: I am a:
___ person with low/no vision.
___ fully sighted person.

I wish to receive the CCLVI publication, Vision Access in:
___ Large print  ___ Cassette  ___ E-mail
___ Audio CD  _____ Data CD  _____ Do not send

Please send the American Council of the Blind Braille Forum in:
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