

BayLines

Fall, 2017

BayLines



**Bay State
Council of the Blind**

Bay State Council of the Blind
57 Grandview Avenue
Watertown, MA 02472
Phone: 617-923-4519
www.acbofma.org

President: Brian Charlson
617-926-9198
brian.charlson@carroll.org

Editor: Bob Hachey
781-893-6251
bhachey@verizon.net

Assistant Editors: Steve Dresser, Jerry Berrier, and Judy Savageau

"BayLines" is published three times per year in large print, via e-mail, and on the Web. Please contact the editor if you wish to request a change of format. Deadlines for receiving material are April 15, August 15, and December 15.

BSCB E-mail Lists:

BSCB-L is an open e-mail list for discussion of topics of interest to BSCB members and friends. To subscribe, send e-mail to bscb-l-subscribe@acblists.org.

BSCB-ANNOUNCE is a moderated one-way e-mail list used to disseminate pertinent announcements to members and friends of the Bay State Council of the Blind. To subscribe, send an e-mail request to: bscb-announce-subscribe@acblists.org.

Table of Contents

President’s Message: Bucket Lists and ACB	4
Meet Our Newest BSCB Chapters	5
Interested in Taking an Accessible Vacation? Try a Cruise	6
“Seeing” the National Parks	9
Hello, My Name is Rose	12
Advocating for Yourself in an Emergency Medical Situation: Advice for People with Visual Impairments	13
On Families, The Passage of Time, and BSCB	19
BSCB Board of Directors	21
Chapter Contacts	22

President's Message: Bucket Lists and ACB

Things continue to get more and more complicated in our lives. If it isn't balancing family, work, and the like, it is trying to be a friend to many people without neglecting any of them.

One of the ways I use to manage my life is through lists. I have many lists, and even have a list of my lists. One of the lists I have been working on as of late is my travel bucket list. I can now proudly say that I have been in 48 of the 50 states here in the U.S.A. I have also been to 20 countries, including the U.S.A.

Traveling for me isn't a matter of going; it is a matter of what I am going to do when I get there. Where did I get to go to eat? What museums did I get to visit? What did I find in that little shop on the main drag? Most important for me is: Who did I get to meet? People are so interesting. I enjoy their different ways of expressing themselves, hearing about their families, learning how they get around, and so on.

While you are reading this in the pages of *BayLines*, this isn't about blindness or low vision; it is about people — the people you get to meet at BSCB events, at your local chapter meeting, while taking advantage of an audio described play or a nature walk along a braille trail.

We work together. We play together. We make friends and sometimes find sweethearts. Please set aside a little time in your day to thank your friends just for being a friend. In the Bay State Council of the Blind, we are blessed to have one another to turn to when we are down, and to count on when we need help. Don't hesitate to ask for help when you need it, or to offer help when

you have something to give. Together we are a community that is interdependent, and proud of it.

—Brian Charlson, President BSCB

Meet Our Newest BSCB Chapters by Steve Dresser

Congratulations to BSCB's newest chapters: the Boston Chapter, and the Central Mass. Chapter.

The Boston Chapter was formally approved by the BSCB Board at its monthly meeting on August 13. According to acting President Frank Ventura, eleven people have expressed interest in the new chapter, and seven people have paid dues, which meets BSCB's constitutional requirement for the minimum number of members in a chapter.

In early September, twelve people assembled in Worcester to begin planning for the creation of a new Central Mass. Chapter. On September 30, seven members paid dues, and the new chapter was formally accepted at the October BSCB Board meeting held on October 8. Since September 30, four additional current memberships were renewed, indicating that the Central Mass. Chapter is off to a good start.

We look forward to lots of activity within our new chapters, and wish them the best in all that they accomplish.

SAVE THE DATES:

The 2018 BSCB Convention will take place from Friday March 9 through Sunday March 11. The location will once again be the

Marriott Hotel in Burlington Massachusetts. Please put these dates on your calendar and plan to join us for plenty of informative presentations, fun, and fellowship. The convention announcement and registration information should be delivered to you no later than February 1, 2018.

**Interested in Taking an Accessible Vacation?
Try a Cruise
by David Kingsbury**

Last summer, I went on my first cruise. I went from Boston to Bermuda. I had such a good time that I did the exact same trip this year. Reason Number One for that was my travel companion – DeAnn Elliott. If you have to spend a full week in close quarters with somebody, you had better get along well with him or her. I'm nuts about DeAnn and still amazed that she puts up with me.

Reason Number 2 was that the cruise was accessible in a way that is rare for vacations. DeAnn and I are both blind. If you are blind and not traveling with somebody sighted, certain vacations are not possible. Want to go hiking in the mountains? Who is going to drive you there? And even if you get to a trailhead, then what? Want to go to the beach? Even if you can find your way to the water's edge, how are you going to get back to your towel after you have come out of the water and the tide has washed you a half mile down the beach?

Even if you can independently travel to, say, New York City, such travel can be stressful. You may still manage to have a good time, but when you get home, will you really feel relaxed and refreshed?

Going on a cruise was different. “Hey! I’m on vacation and it actually feels like one!” I exclaimed to DeAnn on numerous occasions. It was truly restful throughout and I had a blast.

Ironing out possible accessibility challenges takes some preplanning, but not a whole lot. We contacted the cruise line several weeks before traveling with a few requests. We asked for an orientation tour on the first day so we could scope out the ship and begin to figure out where things were and how to get around. We learned that the ship is divided up into three parts: fore, midship, and aft. Each section has a corresponding elevator and stairwell. Once you know that the main breakfast restaurant is on the sixth deck aft, or that the Mexican cantina with tasty margueritas is situated on the twelfth deck midship (margueritas are a priority for DeAnn), you have already fought half the battle in getting there.

We also asked if it would be possible to have a staff member accompany us on shore excursions when we got to Bermuda. We thought this one might be really pushing our luck, but they graciously agreed to provide a staff member. Invariably, the staff members did not mind being on the clock while going to those nice pink sand beaches.

An onboard wifi hookup can cost anywhere from \$80 to \$200. We asked for this as a reasonable accommodation because each day’s program of activities and restaurant menus were passed under the door in hard copy. Getting this information electronically made it accessible. We received free wifi and a staff member consistently emailed this information to us the day before. We could then figure out which activities we wanted to attend and which restaurants had the most interesting fare. Even better, whenever we felt like it, we changed our minds. Rather than go to that pseudo-Vegas show, maybe we just wanted to hang out on the balcony and listen to the waves lapping against the hull. This

introduced a level of spontaneity that comes naturally to sighted people, but which blind people rarely experience when traveling independently. Having the flexibility to just wing it is a big part of what can make a vacation relaxing and free of stress.

Were there still some accessibility problems? Unfortunately, yes. There was no Braille signage for room numbers. Instead of being raised, room numbers were recessed and basically incomprehensible by touch. We eventually discovered a trick or two for finding our room.

In contrast, last year, the cruise company paid a pile of money to recarpet the hallways with a design of little fishies all swimming towards the front of the ship. This was meant to help sighted people figure out what direction they were going in. With all the other visual cues that sighted people have at their disposal, did they also need this kindergarten gimmick to avoid getting lost? Sighted people can be pretty hopeless sometimes!

Throughout the trip, ship staff were warm, friendly, and responsive to our needs. Yet after the first couple of days, the load we imposed lightened, and we were able to handle pretty much everything on our own.

It also helped that the ship docked in South Boston. I took the Ride to the ship the first day and again took it home the last day. Very convenient. Unfortunately, nothing tells you better that your vacation is over than getting back on the Ride. So alas, here I am, back in Boston, daydreaming about a repeat voyage next year.

“Seeing” the National Parks by Laura Griffith

[Editor’s note: This article is reprinted from the summer 2017 issue of the *PCB Advocate*, a publication of the Pennsylvania Council of the Blind.]

The National Parks in our country are a treasure that should be enjoyed by every U.S. citizen. Wishing to see them while I still had vision, I recently had the privilege of touring thirty-five of the parks, as well as a couple of National Historic Sites, with my fully-sighted husband. I have retinitis pigmentosa, which causes night blindness, light sensitivity, and a shrinking visual field. While it was a spectacular experience, there was definitely room for improvement with regard to accessibility for those who are blind or have low vision.

Audio description was one source of frustration. Most parks offer a video at the Visitor’s Center, which provides a history, description, and orientation to the park. These can be wonderful, even if you can’t actually see the park itself. I was absolutely delighted when a ranger approached me at one park (I think it was Black Canyon of the Gunnison) and asked if I was interested in the audio description. What a pleasure to actually be told what was on the screen! From then on, we made a point of asking about audio description at each park, but more often than not, I was disappointed. We were usually told they either did not have audio description, or did not even know what it was. (How many of us have had to explain that, no, we are not deaf?) A few of the rangers either couldn’t find the audio description or did not know how to set it up. Once I was asked to come back the next day, so they would have time to figure it out. Only three times in our travels was I actually able to attend a film with audio description. It took persistence, but what a difference it made!

In spite of the challenges, I would encourage everyone who can to take advantage of this priceless national treasure. Highlights included the awe-inspiring views of Crater Lake and Mt. Rainier, the exhilaration of a mule ride to the bottom of the Grand Canyon, feeling the splash of raging waterfalls or tramping through a snow field in Yosemite in June, smelling the damp earth and spring vegetation in Fern Valley at Redwood, walking the pebble beaches of Olympic, witnessing a profusion of cactus blooms in the heat of Death Valley, listening to the mud pots boiling at Lassen Volcanic, paddling a kayak down the Rio Grande in Big Bend, tasting the delicious fruit pies from the orchards of Capitol Reef, and enjoying the isolation of Isle Royale in the middle of Lake Michigan. Perhaps the most exhilarating moment came when riding horseback through the woods of Stahekin Ranch, in North Cascades. When my horse suddenly began to “dance”, I instinctively grabbed the saddle horn. That kept me from being thrown when he bolted after encountering a rattlesnake! (Why our trail guide had the blind lady leading the group is another story for another day.) Every park had its own character and charm, and I wouldn't skip a single one.

If you are fortunate enough to get to visit the parks, here are a few recommendations:

1. Plan accommodations in advance, as the parks draw big crowds, particularly in summer. We drove in our minivan and stayed in budget motels, where you usually get free breakfast and free wifi.
2. Be sure to pack a hat or visor, as well as assorted sunglasses if you are light sensitive. In the blinding white heat of the southwest, I often wore wrap-around sunglasses over my clip-ons! And don't forget to dress in layers, as temperatures vary drastically from valley to mountaintop.

3. If you have a limited visual field, a reverse monocular device may be helpful for bringing the sweeping vistas into your view. I enjoyed this atop Rocky Mountain and on the cliffs of Channel Island, among others.
4. If you use a cane: wheelchair accessible trails are great. But very few rangers understood the challenges of hiking rough or rock-strewn terrain. In retrospect, I would recommend a pair of hiking poles – especially for steep, rocky trails. I have also used a saucer-shaped tip, which can be helpful on grass and packed sand or gravel.

Fortunately, my husband was very patient, and did his best to warn me of obstacles on the paths. A trail that was supposed to take about an hour would take me closer to two hours — but of course stopping to take a close look at every animal, cactus or wildflower probably added considerably to the time spent!

I am aware that our national parks are strapped for funding. I am also painfully aware that too few blind or vision impaired people seem to visit them. Perhaps this is a chicken-egg situation. But it is unreasonable to expect our government to invest in ranger training or audio description if these services are not being used. It is therefore up to us to take some responsibility. I would encourage anyone with the opportunity to do so to get out and experience these fabulous natural resources. Only if we do so, and request accessibility to at least some of what they have to offer, can we expect to see an improvement in accommodations for the blind and vision impaired. And when we are accommodated, let us not forget to express our sincere thanks to those who take the time and effort to make it possible.

Hello, My Name is Rose by Rose Miller

[Editor's Note: On June 1, Rose Miller was inducted into the Carroll Society as Employee of the Year. Upon receiving this award, Rose read the following poem. Rose is an advocate in the Civil Rights Division of the Massachusetts Attorney General's Office where she has worked for many years.]

Did you hear me? My name is Rose!
I am visually impaired
I wash my clothes
I cook my food
I tie my shoes. Can you imagine what it is like to be blind?
You can't see a thing most of the time
Not knowing whether it is day or night, or whether your clothes fit
all right
Imagine what it is like to be blind!
Do you know that when you are blind that people think that all you
do is sit around and waste your time?
Imagine what it is like to be blind!
I would like for you to know today that I live a life just as you do
I cook my food, I wash my clothes, and sometimes I do the bou-
ga-lou
Imagine what it is like to be blind!
Do you know that when you're blind people put you through silly
little tests,
and they speak to you as if you are deaf?
They ask you questions they know the answer to,
And again put you through another test
Imagine what it is like to be blind!
I cook my food, I wash my clothes, I go to school, I educate
others, and I am also a child of God

I want to thank you all for today and allowing me to speak with you today about this issue
Thank you, And My Name is Rose.

Advocating for Yourself in an Emergency Medical Situation: Advice for People with Visual Impairments by Deborah Kendrick

[Editor's Note: This article is reprinted from *Access World*, a publication of the American Foundation for the Blind.]

One morning I was standing in my bathroom about to get into the shower and prepare for my day when my world literally turned upside down.

One moment, I was standing, mind racing about my clothes, my work schedule, my coffee, my dog — and the next, I had the sensation that my thigh had been struck by a large object and I was instantly on my back on the cool tile floor. I knew immediately that I could not stand up. Slowly, carefully, I scooted backward out the door and across the bedroom, where I could reach a phone and call 911.

The paramedics talked to me on the phone. They told me they'd have to break down a door to rescue me and asked me to choose front door or back. I heard breaking glass, men's voices, and, before long, I was placed on a stretcher and carried down my very steep stairs to the cold outdoors and the waiting ambulance. "Two things I need you to get," I told them. "My guide dog and my iPhone."

Later, there would be a stretch of hours when I remembered none of this, but in that window of crisis, with no one but me to

advocate for me, I gave clear directives. I told them how to fasten my golden retriever's guide harness and told them where the iPhone and its charger were located. In the ambulance, I called my daughter 1,000 miles away so that someone knew where I was going.

It turned out that my left femur, the longest bone in the body, compromised by cancer a decade earlier, had snapped and displaced. I spent eight hours in the emergency room, during which time my surgeon explained to me that serious reconstructive surgery was scheduled for the next day. A metal plate about eight inches long would be screwed to my bone and wired to my hip. The recovery period, during which I would be unable to bear any weight on that leg, would last about three months.

Nothing to Do with Blindness

Like many Access World readers, I am a seasoned veteran of blindness. I mastered my alternative techniques long ago and think about blindness very little, if at all.

I live alone, manage my own home and work life, travel independently with a guide dog or white cane, and have a delectable array of technological tools to make everything from writing a book to color-coordinating a room manageable without sight.

My injury had nothing to do with blindness. My getting to the phone in a familiar environment didn't either. Directing the paramedics to get my dog and phone was, if anything, easier for me as a blind person because I know how to use my words to describe objects and their locations.

Once I was in that hospital, however, my familiar ground was gone. My daughter had immediately called two close friends who met me at the emergency room and they told me that, from my blurred state of shock with morphine added, I repeatedly asked, "Where am I and how did I get here?"

Of course, as blind people, independence is deeply rooted in our ability to take control of our own lives. Essential to taking control is the basic awareness of "Where am I and how did I get here?"

I was in the emergency room for eight hours before a room in the Joint and Spine Center of the hospital became available. About halfway through that time, my brain cleared and I became aware that I needed to be alert, to be my own advocate. While my blindness and hearing impairment are inconsequential to me on a daily basis, they were front and center to these medical professionals who did not know me. Advocating for myself was a matter of survival.

My gratitude is abundant for many things that occurred that traumatic day, but two particularly fortunate facts were that I was in a large, flat room rather than on a staircase when my femur fractured, and that my hearing aids were in my ears. Without them, communicating with paramedics or emergency medical personnel would have been next to impossible.

I had been in shock. I was in excruciating pain. I was told not to sit up or move my leg in any way as I could further displace the broken parts. Time and an IV drip of medication gradually returned my lucidity and I knew communication was key.

A first step toward self-advocacy was to ensure that my hearing aids could stay in my ears before, during, and after surgery. Without them, I explained, I might miss questions or information in preparation or recovery. Permission was granted. As it turned out,

I never took both hearing aids out throughout my three-week hospital stay. Not being able to see people come and go, I knew I needed to hear them.

Next was establishing a certain style of communication with staff. While being transported to my hospital room, I began what would be my signature survival tool throughout my stay: engaging each person in dialogue and asking questions. What floor are we going to? What is the room number? What is the name of each drug you are asking me to take and what is its purpose? (I happen to have a high sensitivity to all medications; so many routine doses were adjusted in these preliminary conversations, which helped me maintain clarity while also building relationships with medical staff). And about the medical staff. When you are in the hospital, a steady stream of people come and go, with shifts constantly cycling nurses, personal care assistants, doctors, physical therapists, occupational therapists, social workers, and housekeepers on and off duty. They might wear different colors and/or name badges, but for me, a blind person who doesn't have particularly stellar voice recognition skills, asking people to identify themselves was another key factor in maintaining my quality of care and well-being.

At the foot of my bed was a monitor that displayed various kinds of constantly updated information specific to my treatment. Information is essential to advocating for oneself. The kinds of information updated at the foot of my bed included the name of my nurse and personal care assistant, my schedule of physical and occupational therapy, meal times, and special events available to patients (such as healing touch or yoga). It was all right there for me to read at any time, but in print and therefore completely unavailable to me.

Keep it Light

Whether you are an introvert or an extrovert, keeping a running dialog going in this kind of situation is integral to survival.

Sometimes I asked questions in a straightforward way: "Can you put a note in my chart for staff to identify themselves when they come in? I'm good at being blind, but never did very well in the voice recognition department." Or, "Can you read my board to me? They haven't put one up in braille yet." In other words, I was clear about my needs, but tried not to communicate those needs in any way that might be perceived as strident or critical.

I was there, as you recall, because my femur had fractured. I had had serious reconstructive surgery, and had to learn new skills like how to transfer safely from the bed to the wheelchair and from the wheelchair to the toilet or shower bench, how to stand up on my one good foot when necessary and not lose balance, and much more.

Even though my being there had everything to do with my leg and nothing to do with my blindness, rare was the nurse or aide who did not ask, "So, exactly what can you see?" Again, I tried to keep it light, but doing so and remaining patient wasn't always easy.

I frequently said things like, "I see with my hands. If you put my hand on it, I will see where it is." If accompanied by a relevant demonstration, that explanation was generally pretty effective.

I quickly learned to make sure everything I needed was within reach before a newcomer left the room. If a technician came to draw blood and moved my laptop out of the way to reach my arm, even though it was six inches away, that laptop was essentially invisible to me. I learned to make quick checks to locate the emergency call button, my iPhone, laptop, and water pitcher each time I returned to my bed or wheelchair from the bathroom or the

physical therapy gym, or after any staff person had come to call. When moving about is next to impossible and a needed object has been moved from, say, the table on the left side of the bed to the table on the right, locating it is problematic for someone who can't see. I found that by routinely checking and interacting with staff about this environmental checklist, people learned and became much less likely to inadvertently move objects from one place to another.

Payoff in Wellness

While it might sound a little exhausting (and sometimes it can be), my continually engaging in conversations with all those responsible for my care enabled me to focus on getting stronger and getting well. Even while rooted in a hospital bed, unable to move without assistance, we can still advocate for ourselves, control our own environments to a point, and thus maintain our independence. The physical therapist who was at first troubled that I had no eyesight was laughing with me as I "drove" my wheelchair down the hall. Staff who began noticing that I was constantly using my laptop and iPhone eventually caught on to texting me my therapy schedule every evening as an alternative to expecting me to read that inaccessible monitor at the foot of my bed.

The doctor who discharged me told me that I was being released at 18 days rather than the anticipated 24 because I was "so fiercely independent" and determined "not to allow a disability to be a disability." Interpret that as you will, but I believe what actually facilitated my speedier release was that by advocating for myself, I took the emphasis off my blindness and put it where it belonged: on my accident, surgery, and recovery. The payoff was that many members of the medical team learned something about blindness in the process and I was able to get home for Christmas!

On Families, The Passage of Time, and BSCB by Bob Hachey

This month, I am putting together this issue of *BayLines* with a heavy heart. My wife Donna and I lost her dear sister Gail on September 10 to liver cancer at age 53. We were very close to Gail; she was not only Donna's sister, but her best friend as well.

Gail Tucci-Lampron was the most positive person I've ever met. She brought bright sunshine into every aspect of her life. Last summer, Donna and I attended Gail's second wedding. Observing Gail and her new husband Phill together reminded us of a young couple very much in love, as we were 36 years ago. At the time, Gail was also working toward her master's degree. She was planning to develop a training program at a local community college for operating room technicians in the spring of this year.

But all of her wonderful plans changed when she was diagnosed with cancer in March of this year. Her last six months were very difficult ones. For those of you who have never had to watch a loved one be taken by cancer, I hope that is something you never have to experience. Frankly, I can't imagine what Phill is going through right now.

Losing someone like Gail before her time has made me think long and hard about what is really important in life. It often seems that I get caught up in the task of the moment and don't place enough of a priority on spending quality time with friends and loved ones. We all have a variety of families. There is, of course, the traditional family consisting of parents, children, spouses, partners, brothers and sisters. But there are also the families created by a common workplace or a common interest. In the case of BSCB, we all share vision loss as a commonality, either directly or indirectly.

I am going to redouble my efforts to live in the moment when it comes to spending quality time with the members of all of my families including the membership of BSCB. In the past, I have often found myself saying things like, "Hey, it's been awhile since I spent time with my brother. But I'm busy this weekend and there are other weekends." I could have said that about other friends and family members as well.

Losing wonderful people like Gail Tucci-Lampron, and Marcia Dresser two years ago tells me that opportunities don't last forever and are sometimes fleeting. I encourage all of you to keep your families and friends close to your heart. We all get caught up in the rush that is everyday life. Let us all try harder to prevent everyday life from getting in the way of spending time with the people who mean the most to us.

BSCB Board of Directors

Brian Charlson, President
Phone: 617-926-9198
Email: brian.charlson@carroll.org

David Kingsbury, First Vice President
Phone: 617-974-2001
Email: davidkingsbury77@gmail.com

Frank Ventura, Second Vice President
Phone: 617-267-1067
Email: frank@littlebreezes.com

Jerry Berrier, Secretary
Phone: 617-294-2384
Email: Jerry.berrier@gmail.com

Rick Morin, Treasurer
Phone: 781-373-1044
Email: rick.morin@comcast.net

Rose Miller, Director
Phone: 617-963-2476
Email: rosemarymiller3@verizon.net

Mary Haroyan, Director
Phone: 508-853-6445
Email: mharoyan@charter.net

Carey Scouler, Director
Phone: 617-957-5726
Email: cascouler1990@gmail.com

Chapter Contacts

Charles River Chapter
Anne Donna, President
Phone: 617-926-8836
Email: annemdonna@aol.com

South Shore Chapter
Kathy Devin, President
Phone: 617-472-0308
Email: kcdevin@verizon.net

Boston Chapter
Frank Ventura, President
Phone: 617-267-1067
Email: frank@littlebreezes.com

Central Mass. Chapter
Emily Miranda Luz, President
Phone: 508-523-7303
Email: emily.buresh@yahoo.com

Guide Dog Users of Massachusetts
Minh Ha, President
Phone: 774-242-4860
Email: Minh.ha927@gmail.com

Bay State Council of the Blind Students
Daisy Russell, President
Phone: 781-535-9366
Email: siobhan.daisyrussell@gmail.com