

BayLines
Fall, 2014

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President's Message

BSCB Board Briefs

by Bob Hachey

In August of 2014, the BSCB board spent a good bit of time in planning of the fall Conference. We also did a debrief of the ACB National Convention. It was agreed by all that ACB President Kim Charlson did a fantastic job running the convention. Kim was presented with a BSCB life membership sponsored by BSCB. We discussed the production of Baylines and a detailed treasurer's Report. WE all agreed that BSCB needs to do more fundraising in order to defray expenses.

In September, the board finalized plans for the Fall Conference. WE decided that the 2015 BSCB convention would take place on the weekend of March 27 at the Burlington Marriott. Please mark that weekend on your calendars. WE authorized the following expenditures: \$500.00 to support the disability Policy Consortium; \$150.00 for a Legal seafood gift certificate for the ACB auction; and \$350.00 for White cane Safety Day. Marcia informed us that the BSCB North Shore Chapter would hold its first meeting in the month of October. Look for more information on the North Shore Chapter later in this issue. WE agreed to participate in efforts to increase the accessibility of Netflix.

In October, we first received a report on the creation and first meeting of the BSCB North Shore Chapter. WE then discussed increasing expenses for the Spring Convention. We decided to remove the room subsidy for those staying in the hotel on Saturday night. The keynote speaker for the 2015 convention will be Dan Spoon of Florida. We authorized the following expenditures: \$300.00 for Our Space Our Place; \$100.00 for National Braille Press.

Living with Usher Syndrome: A Partner's Perspective

by Megan Sullivan

(Megan Sullivan is Associate Dean for Faculty Research and Development and Director of the Center for Interdisciplinary Teaching and Learning at Boston University. She has taught at BU for 18 years now, and she has also published one book, one collection of interviews and dozens of articles and essays. Megan

is married to Carl Richardson, who is the ADA Coordinator for the Massachusetts State House. She can be reached at msullivan@bu.edu.)

I don't live with Usher syndrome. Not really. My husband does, so I'm a bit like a not-so-silent bystander watching and participating in his journey. Earlier this year, I read a blog post entitled *Taboo* by Mark Dunning, Founder and Chairman of the Usher Syndrome Coalition, with interest and had two reactions: I thought Mark's words were generous and brave and smart, and I also thought parents and families might want to hear from a person who lives with an adult who has Usher syndrome. Parents and families could then imagine what their children's and family member's lives might be like someday. This is a tall order, as my husband is more than merely a case-study in Usher syndrome; he is one of the most unique men I've ever met. Carl is smart and funny (albeit not as funny as he thinks he is), hardworking, responsible and still handsome at forty-seven. Carl's career means he advocates all day, every day for people with disabilities. Perhaps because of this, he is circumspect about how he understands his own; Carl's view is everybody has something to contend with, and there are disabilities far harder to navigate on a daily basis than Usher syndrome.

Carl was raised with a sister who also has Usher's (Annie is married, has three children, and a career she enjoys); and by parents who were incredibly devoted to their children and who raised Carl and his sister to do what they could and to believe they would lead happy and fulfilling lives, just as would their siblings who did not have Usher syndrome. Carl and I were a bit older when we met; he was thirty-five, and I was thirty-eight. We both had spent time developing our careers, traveling, and enjoying life with friends and family. Carl had always assumed he would get married someday, while I didn't necessarily believe I would partner for life. I had been raised by a single parent, so marriage didn't necessarily seem the norm to me. I also wanted to continue to be a writer and teacher; I thought marriage would take too much time away from these pursuits. And then I met Carl, and I couldn't imagine not partnering for life with him. This September we'll be married for ten years. Like all marriages, ours has been shaped and molded in accordance with our separate and distinct personalities. We've learned to contend with each other's foibles: Carl has worked hard to keep our house as neat and clean as I like, and I have endeavored not to notice the electronic gadgets and computer wires that breed like mold in our basement. We're also reminded daily of our shared commitments – to each other, to our families, and to our vision for our community and world. I think it's these shared commitments that keep us so connected; we believe in the same things, and we want the same outcomes.

So what does all this mean for Usher syndrome? Perhaps paradoxically, it means everything and nothing. Maybe that's what Mark meant when he wrote in his blog that his sadness had everything to do with Usher's and, I presumed, nothing to do with it. Living with somebody who has Usher syndrome is one of the defining characteristics of a family's life and at the same time one of the least consequential. The fact that Carl is hearing impaired (he wears two hearing aids) and visually impaired

(he was declared legally blind at 28; is on his second guide dog; and loses more of his sight every year), certainly informs our daily life. Carl sometimes gets frustrated and tired; I imagine it is physically exhausting to work so hard to see and hear all day, every day. I imagine it is emotionally demanding to work so hard all day, every day to reassure non-disabled people that despite what they might believe, your life is just as good and full and irksome as is the next person's. Although Carl works hard not to let it, his frustration affects us. He can be quick tempered and impatient. I can be moody and sensitive. His temper and my sensitivity have something to do with his disability, but they also have nothing to do with it: we are individuals, and our personalities are what they are. Carl was unemployed for a while early in our marriage, and his unemployment had a lot to do with his disability; unemployment affect all members of a family, so that was a challenge for us. Usher syndrome means Carl no longer drives, so even though I have never liked to navigate the roads, I now do it all. This is not ideal, but then again I don't have a house overlooking Big Sur like I once dreamed I would either. Finally, Carl and I don't have children, but that's much more my decision than his, and it has much less to do with Usher syndrome. Just as I never assumed I'd marry, I also never had the desire to give birth. Add to that the fact that I've always been a very responsible person – I've always done a lot for and with my family, friends and community – and you'll understand why I didn't necessarily want the responsibilities I knew parenthood would bring. Would I have had children with Carl if I had wanted them? Absolutely. Would I have known that Carl would have been a fantastic father and that I would nevertheless have had more than my share of the child rearing responsibilities? Yes to that as well. But do you see what I mean? Usher syndrome has something and nothing to do with any of this.

Six months after Carl asked me to move into his Cleveland Circle apartment with him, we discussed marriage. Because I knew that in the not-too-distant future he would definitely lose all his eyesight, I asked Carl what he would do if he also lost all of his hearing. (Carl is diagnosed with Usher syndrome II, so he is not "supposed" to completely lose his hearing, but one never knows.) As befits his personality, Carl was matter-of-fact. He'd deal with it, he said. At the time, his response struck me as unsatisfactory. How exactly would he "deal" with it? Would he get a Cochlear implant? Would that suffice? Would he still be able to work, and how would he listen to his beloved books? If we got married how would I communicate with him? How would I just "deal" with the fact that my husband had neither eyesight nor hearing?

It has been over eleven years now since Carl and I had that discussion. I no longer worry about whether and what we will do if Carl loses his hearing; I think about it sometimes, but I don't worry about it. Partly this is because we've taken sign language classes; partly it is because we know people who have had success with Cochlear implants. It is also because I know that if it happens, I'll deal with it. Carl and I will deal with it together because that's what you do in a marriage and when you love someone. You deal with whatever comes along, and you know it will be fine. And by some miracle it is.

(Editor's note: The blog post referenced above can be found at

<http://www.usher-syndrome.org/index.cfm/event/blog.detail/blogId/11582#blogTitle>)

Making the difference One Customer at a Time

Verizon Wireless Opens the National Accessibility Customer Service Center to Address Special Needs for Customers

By Paul Macchia

The customer comes first -- but not every customer has the same needs. Some have special circumstances and require a tailored service which addresses their nuance.

As part of the Verizon Credo, "We focus outward on the customer, not inward. We make it easy for our customers to do business with us by listening, anticipating and responding to their needs."

On October 15, Verizon Wireless unveils the National Accessibility Customer Service (NACS). Designed to support people with special needs and requirements, the Charleston, South Carolina-based center will be staffed with approximately 200 dedicated representatives to address individual mobile needs – whether it is providing guidance on device selection, technical support or account transactions.

The dedicated phone number for the center is 888-262-1999 and its hours are Monday through Friday, 8:00 a.m. to 5:00 p.m. (local time zone). Depending on geographical location, if customers call after these hours, the call will be handled by other Customer Service and Technical Support representatives who are available from 6 a.m. until 11 p.m., (local) seven days a week at 800-922-0204 or by dialing *611 from a Verizon Wireless phone.

Customers can also utilize our Chat services found on VerizonWireless.com. As we look to the future we will be including the ability to take point to point video calls directly from our customers who need to contact us using American Sign Language.

A general consensus by many polls and analysts suggest that approximately 19% of the American population has a disability. One of the primary mechanisms of communication for this

demographic is by mobile devices and apps. For wireless customers with disabilities, using devices for communications is imperative, followed by the apps that facilitate.

The value of wireless services means a lot to customers in this demographic as they use them for personal and business communications. They also want the satisfaction and sense of independence of figuring out how to operate the phone by themselves.

Some of the inquiries and challenges the representatives will be able to address include:

Finding specific applications for customers depending on their needs, recommending devices, providing instructions on how to use certain features. As well as reviewing the products and services we have available today for these customers and discussing the best pricing plans for the customers' needs.

“People want the satisfaction and sense of independence of figuring out how to operate a phone by themselves,” said Barbara Kaplan, senior consultant, national marketing sales operations and support, Verizon Wireless. “Our National Accessibility Customer Service center will be able to work one-on-one with a diverse customer base and ensure they have everything they need for their communications needs in their mobile lifestyle – whether it is business or personal.”

BSCB Chapter Reports

by Bob Hachey

Charles River Chapter

BSCB's Charles River Chapter is doing its usual thing. WE had our summer time pool party and barbecue on August 23 at the home of Kim and Brian Charlson and a good time was had by all. This party features good food, fellowship and a very nice pool heated to 80 degrees. WE had our fall meeting on October 18 and had the chance to hear from Subhashish Acharya, founder of Project Starfish which is a small startup dedicated to finding project-based employment working with a wide variety of small businesses. Starfish also offers training opportunities for its members. Acharya hopes that Starfish will serve as both a training ground and a bridge to full- and part-time employment for visually impaired persons all around the world. This meeting also featured brief discussions regarding how to deal with snowy sidewalks in winter and accessible voting.

Guide Dog Users of Massachusetts

GDUM had a well-attended meeting on November 8. WE began with social time and pizza. WE had a lengthy discussion of a new policy whereby the MBTA now puts all passengers traveling with service

animals in vans only. It was agreed by all in attendance that one size should not fit all and that some guide dog users should be able to ride in the cars. A GDUM committee will be working with the MBTA to make changes in this new policy. GDUM is interested in learning about the experiences of guide dog users who have used services such as Lift and Uber for transportation.

South Shore Chapter

The south Shore chapter met on October 18th. There were 16 people in attendance. The meeting was at Jamie's restaurant in Braintree. Elections were held and Kathy Devin was elected president, Dennis Brady Vice president, Chris Devin Secretary and JoAnn Kershner as treasurer. Marcia Dresser, also attended the meeting. Dews were also collected. We plan to hold our next meeting in January or early February.

(Editor's note: It is hoped that we will have reports from all BSCB chapters in future issues of Baylines.)

Pedestrian Travel in Winter, or How to Deal with Snowy Sidewalks by Bob Hachey

Pedestrian travel or walking is something that many of us do a lot of as blind and visually impaired persons. WE walk to get from point A to point B, for exercise, or simply for the joy of walking. Since we cannot drive, I'd venture to say that many of us walk more than our car-driving counterparts. Personally, I walk for all three reasons listed above. I often find that a brisk walk is either a welcome break in a long day or a reward for a long day spent.

AS much as we enjoy walking, it certainly takes more motivation to get out there and walk during the cold, snowy and icy winter months. AS a life time resident of the Boston area I have always figured that the cold can usually be dealt with by obtaining good quality cold weather gear and just getting out there and putting one foot in front of the other. After all, I still have places to go and I'd rather not curtail outdoor exercise in the winter unless absolutely necessary. My outdoor gear includes wool socks, winter-proof boots and shoes, heavy coats, gloves, a wool hat and a face mask. There's one other piece of equipment I'll describe in more detail later on in this article.

Now that I'm all bundled up and protected from the cold, I'm ready to venture out. But wait! AS soon as I step out of my gate and onto the sidewalk I notice that it is covered in two feet of snow! Now what do I do? No doubt about it, snow and ice make pedestrian travel more difficult for anyone, but this difficulty

is considerably greater for a blind person. I recall that some of my teachers at Perkins referred to snow as “blind man’s fog” and ain’t that the truth! It obscures curbs, curb ramps and walk buttons. It turns walks that were once simple into hiking and even mountain climbing.

So, what is the pedestrian to do? Firstly, here are a few techniques to help you get around in the snow. Once the roads have been plowed, you can usually follow the shoreline of the road with your cane. That shoreline is usually a snowbank that has been pushed to the edge of the curb. This technique works well on quieter streets but can be very dangerous on busy streets.

The next time we get a storm of at least six inches, have a sighted friend or family member go for a walk with you in your neighborhood. I have noticed the following patterns on busier streets. IN many cases, one side of the street has a clearer sidewalk than the other. This is caused usually either by one side being sunnier or by more businesses on one side than on the other. Once you learn which sides of streets are clearest, you will be better able to get where you need to go.

For icy conditions, I recommend the use of anti-slip devices that fit onto the bottoms of your shoes or boots. These devices dig into the ice which makes walking on it considerably safer. The ones I use are called Yak Trax.

They’re sort of like rubber bands that fit around the bottoms of your shoes. They have metal coils on the bottom that dig into the ice. Mine came with a nice little carrying pack which is a must since the Yak Trax are usually rather dirty when you take them off. Yak Trax can be found on Amazon and other retailers.

But, if you think about it, we shouldn’t have to be walking on snowy sidewalks. Most cities and towns have some sort of ordinances that require that sidewalks be cleared within one or two days after a storm. Some cities such as Cambridge have policies that require removal or treatment within 3 hours after a storm. But, with rare exceptions, these policies are not very well enforced. What is needed here is some good old-fashioned grass roots advocacy. And, this advocacy must be done at the local level.

I found an excellent report on this subject at www.walkboston.org. Walk Boston is an advocacy organization which promotes more walkable communities throughout the united States. This report is entitled “The Snow Report” and can be found in its entirety at www.walkboston.org/sites/default/files/snowReport.pdf

I believe that we would do well to collaborate with Walk Boston as we have in common the desire for safer pedestrian travel.

Below, I have summarized some of the salient points made in The Snow Report.

“clearing snow and ice from sidewalks, curb ramps, and crosswalks requires careful planning and coordination by municipal officials and property owners to overcome three basic problems:

1. Responsibility is divided. A patchwork of regulations is enforced by many different municipal and state agencies that may not coordinate their clearance, regulations or enforcement.
2. There is no central point of contact. Private citizens often don't know whom to contact with a question or concern, especially when they are uncertain whether the municipality, a property owner, the State, or an agency is responsible for clearing a certain sidewalk.
3. There is inadequate enforcement and awareness. Even in communities with good sidewalk clearance regulations, the rules are often disregarded because:
 - Property owners simply don't know about the requirements.
 - Property owners do not understand the importance of clearing.
 - Property owners cannot manage due to health problems or age.
 - Lax inspection and enforcement leads property owners to ignore the regulations without suffering any consequences.

Some communities have made a concerted effort to address snow and ice clearance; in others little attention is paid. Most often, the issue receives attention because one or two key policy-makers are serious about sidewalk clearance and set the tone for the community as a whole. Year-round walkable sidewalks are needed by all pedestrians, and deserve attention from policy-makers, municipal and state employees, residents, and local businesses.”

“Removal of snow and ice from sidewalks, curb ramps and crosswalks is as important as clearance from roadways and there is a clear municipal responsibility for ensuring that it happens. Clear, reasonable and enforceable policies should be established, with a system in place to ensure they are carried out. Municipalities should make private citizens aware of their responsibilities and also spell out and execute the responsibilities of the public sector.

Seven key means to improving sidewalk clearance are:

1. Create a norm of snow and ice clearance through social awareness campaigns.
2. Identify a municipal point person for snow removal.
3. Set priorities for sidewalk snow clearance.
4. Improve monitoring and enforcement.

5. Design sidewalks for easier snow removal.
6. Train municipal and private snow plowing personnel.
7. Create sensible state policies through appropriate legislation.”

“Ideally, sidewalk snow removal policies should specify:

1. The municipal department(s) responsible for monitoring snow clearance.
2. The municipal department(s) responsible for enforcement.
3. The penalties for non-clearance or insufficient clearance and how the fines are collected.
4. How clearing of sidewalks adjacent to public property will be handled and enforced within municipal government.
5. Who will clear neglected sidewalks and how the responsible party will be billed for the service.
6. Who will provide services to those who, due to age or disability, cannot clear the sidewalk in front of their property, whether they are able to repay the cost or not.”

Conclusion:

Many of our Watertown members have worked closely with the Watertown Commission on Disability and government officials to construct a snow removal policy for business districts. While this is a very good policy, it is not always enforced very well. Thus, if Watertown residents want clearer sidewalks they will need to be vigilant when it comes to filing complaints and seeking to cause a situation whereby government officials will make enforcement of snow removal policies a higher priority.

In the end, what is needed here for us to have a clearer path to travel is to work closely with commissions on disability and local officials to construct new policies or to enforce existing policies. WE need to find local officials who will champion this issue. Anyone who wants to learn more about this issue or work toward clearer sidewalks in your communities may feel free to contact me or read the Snow report in full.

New Comcast service boosts TV for the blind

By Hiawatha Bray

| GLOBE STAFF NOVEMBER 12, 2014

Kim Charlson is blind, but she loves television. Her favorite show is “NCIS,” the naval crime series. And thanks to new technology from Comcast Corp., it will soon be a lot easier for Charlson and other blind fans to tune in. The cable television provider’s X1 digital service will soon feature a “talking guide” that will read out channel listings and program descriptions in a lifelike electronic voice. Blind users who “view” TV programs by listening to them will now find it easier to change channels, track down their favorite programs, and program their digital video recorders to copy shows.

On Tuesday, Charlson demonstrated the new talking guide at the Perkins School for the Blind in Watertown, where she works as library director. She said the talking guide lets her channel-surf like any sighted person.

“I always wondered why they would say there’s 200 channels and I can’t find a thing to watch. That’s how I always felt,” Charlson said. “At least now I can identify what’s on all those channels.”

The talking guides will become available to all X1 subscribers nationwide over the next few weeks.

Users won’t have to get new equipment; the system runs automatically over Comcast’s data network.

“It’s cloud-based, so we didn’t have to worry about installing additional hardware or software in a box,” said Tom Wlodkowski, Comcast’s vice president of accessibility. He is also a veteran of the National Center for Accessible Media at the public television station WGBH in Boston.

Cullen Gallagher, a 16-year-old from Quincy who’s an 11th-grader at Perkins, isn’t a big TV fan. But the new talking guide could change that, he said.

“I want to see what’s out there on the TV networks,” Gallagher said. “I’m just going to play around and look at the menus. I’m a geek. I like to play with technology.”

Comcast said the talking guide is the first offered by any cable company in the United States. It was developed in response to the 21st Century Communications and Video Accessibility Act, a federal law enacted in 2010. The legislation requires cable companies to start offering audible menus to make onscreen commands usable by people who have vision problems.

The talking menu system works in conjunction with another federally mandated service, descriptive video. This is a service in which a voice describes on-screen action during a TV show, saying things like, “Jack Bauer draws his gun.” The nation’s nine most popular broadcast and cable channels must offer these descriptive services on at least four hours of programming every week.

The combination of descriptive video and spoken channel guides will make TV a more immersive experience for about 8 million Americans with vision disabilities.

“TV is more than just a box with a picture in it,” Charlson said. “It’s our culture and our society, and people spend a lot of time talking to each other about what they watched on TV last night. It’s important to be a part of that conversation.”

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