**The**

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**Advocate**

**Spring Edition 2019**

**PCB- A Peer Network for All Impacted by Vision Loss**

PENNSYLVANIA COUNCIL OF THE BLIND

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MISSION

To promote independence and opportunities for people with vision impairments.

VISION

To continue to be recognized as the leading advocacy organization for people with vision impairments in Pennsylvania. The aim of all our efforts is to encourage and assist people in achieving their potential as valued members of society. PCB assistance, advocacy, and encouragement will be carried out in such areas as, but not limited to, all aspects of accessibility, transportation, education, and employment.

The PCB Advocate is available by network subscription in large print, braille, audio cartridge and email. Send changes of address or format preference to the PCB office. Contents are available to the public via pcb1.org and our information line at 773-572-6314.

EDITOR’S NOTE

Articles in this publication reflect the views of the individual writers. They do not necessarily represent the views and policy of the PCB.

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Audio Production: AccessiDocs Team

 Braille Edition: Horizons for the Blind

SUBMITTING ARTICLES

If you wish to submit articles for consideration, submission deadlines are March 1, June 1,

September 1 and November 20

Send articles to ADVOCATE,

c/o Sue Lichtenfels Email- advocate@pcb1.org or 96 Robb Hollow Road, Pittsburgh, PA 15243.

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National Conference Stipends Available

Surely you’ve heard by now that the American Council of the Blind will hold its national conference in Rochester, New York July 5-12, 2019. Information about the conference is available at ACBConvention.org. PCB encourages its members to take advantage of the conference’s close physical proximity to Pennsylvania. PCB is excited to offer six stipends of $250 each to our membership to aid attendance. Funds may be used for overnight accommodations, travel, meals, or conference activities.

Applicants for PCB stipends must be attending the ACB national conference for the first time. He or she must have been a dues-paid member of PCB for 2018 and must maintain current membership. If selected, he or she must pre-register for the conference with ACB and show proof of conference pre-registration by June 10. The stipend check will be mailed upon receipt of this verification. Stipend awardees will be expected to participate in the conference for a period of at least two full days.

To apply for one of the $250 stipends being offered by PCB, members must send a letter explaining the following:

1. What do you hope to gain by attending the ACB national conference?
2. How have you demonstrated your interest and involvement in the work of PCB either through a chapter or on the statewide level?
3. What do you foresee for your future participation in the council?

Letters of application should be submitted to the PCB office by April 15, 2019. Winners will be notified of the award the first week in May. Submit letters by email to pcboffice@pcb1.org or by any other format to: PA Council of the Blind, 931 N. Front Street, Suite B, Harrisburg, PA 17102. Should you have questions, please contact Mary Ann Grignon, Membership Coordinator at 570-807-1276 or maryanna0407@gmail.com.

Council News Clips

**Get your Raffle Ticket Soon**

The PCB Calendar Raffle is a six-month-long opportunity to win cold, hard, cash. Each day, from April 1 through September 30, a winner will be determined based on the Pennsylvania evening Pick 3 number. During that period, we give away six holiday prizes of $125, special prizes of $75 on the first and fifteenth of each month, and $30 for each other day. Tickets for all 183 opportunities to win are only $20. To purchase a ticket, contact the PCB office at 877-617-7407 today or ask one of our local chapters about a ticket.

**Reminder Calls Begin**

PCB is piloting the use of a service to make reminder calls about our upcoming discussion calls and notification of other important action updates. Right now, all members for whom we do not have an email address have been added to this automated calling service. Since those members with email have access to reminders via the PCB-L listserv, they were not automatically added to the calling service list. If you have an email, but would like to receive reminder calls, or if you would like to be removed from the automated calling list, please contact Christina in the PCB office.

**Future Leadership**

This is an especially important year for PCB because we will be holding officer and board member elections at our 2019 conference. Our current President and First Vice President have reached their term limits in their respective offices. The other three officer positions of Second Vice President, Treasurer and Secretary are also up for election, but the individuals in these positions can stand for re-election to them. There will be four board positions up for election as well. Please begin to carefully consider whether you would like to run for a position or encourage those you feel would be good leaders to consider running. Please contact Tony Swartz, the Nominations Coordinator to suggest a candidate or express your own interest in running. Reach him at tbswartz@ptd.net or by phone to 610-799-4565.

**Seeking Member Audio**

The Communications Team wishes to spotlight the talents of PCB’s members through the special, “Member’s Mic” section of the PCB Information Line. The team seeks audio MP3 files of members demonstrating their talents through podcasts they’ve created, poetry or prose they’ve written and read, music they’ve written and/or performed, interviews they’ve given, inspirational or educational talks they’ve conducted, etc. If you have audio for the team to consider, please email it to Ed Facemyer, Information Line Coordinator at efacem@verizon.net. Ed may also be able to help you capture the recording if you discuss the idea with him at 610-647-3365. And don’t forget the PCB Information Line is available 24/7 by calling 773-572-6314.

**ACB Exhibit Opportunity**

PCB will be reserving a vendor table in the exhibit hall at the upcoming ACB Conference and Convention in Rochester. On Sunday and Monday, Kathy Keck will fundraise for PCB with her Loving Touch Connection products. PCB seeks opportunities among its members and chapters to use the other days in the vendor hall for additional fundraising. If you have a product or collection of products that would be of interest to the more than 1,000 conference attendees, PCB may be able to offer you space at its exhibit table provided PCB would receive a percentage of the profits. If you are interested in discussing this opportunity, please contact George Holiday, Fundraising Coordinator at 215-796-9813 or George.holliday@comcast.net. In addition, we will be seeking assistance to help staff this exhibit table. Please let George know if you will be in Rochester and can volunteer a few hours for PCB.

Seeking Feedback on BBVS Services

Pcb1.org/survey or 877-617-7407

PCB has developed a survey to gather feedback on the quality of services being provided by the Pennsylvania Office of Vocational Rehabilitation’s Bureau of Blindness and Visual Services, which we refer to as BBVS. The survey will be open for your feedback until April 30, 2019.

We encourage all who have applied for services from BBVS within the last five years to provide feedback through this questionnaire. The data gathered will be used by PCB to determine if there are trending areas of concern being experienced by BBVS clients. Aggregated results will guide our efforts to seek improvement and to insure high quality blindness rehabilitation services in our Commonwealth.

To clarify, the survey is being conducted completely independent of BBVS. It is open to all, not just members of PCB. Please spread this link: pcb1.org/survey throughout the blind and visually impaired community across Pennsylvania.

Completion of the survey is on a voluntary basis, however, in appreciation, we will enter each respondent in a drawing to win one of three $50 Amazon gift cards. If you wish to be entered to win, please provide your name, phone, and email address at the end of the data collection. If you provide us with the name, phone, and email so that we may collect survey data from an additional PA resident who has received BBVS services within the last five years, we will submit an additional entry in your name for the gift card drawing.

The survey should take approximately 20 minutes to complete either by phone or computer. Unfortunately the Survey Monkey platform is not accessible with smartphones at this time. Using a computer, visit pcb1.org/survey and click on the “Begin the survey” link. If you prefer to submit your survey by phone, please contact the PCB office at 877-617-7407.

Thank you in advance for helping us to improve blindness rehabilitation services.

Challenging Our Beliefs

By Sue Lichtenfels, PCB President

We announced at our February 27 open house call the theme for this year’s PCB Conference and Convention: “Peers Challenging Beliefs.” I’m excited to have this as our theme this year because it truly captures the work of PCB. I’ll expound more on that in my address to the convention as we open the conference weekend. I also love the theme because challenging beliefs is in my DNA. I lead by challenging beliefs across many contexts because neither individuals nor organizations can grow and succeed if no one is asking “What if…?” With this in mind, each of my articles this year will focus on challenging beliefs. Let’s start with our role within the council.

Have you ever considered that the word member begins with me? Traditionally, people become members to get something for the proverbial “me.” It’s a quid pro quo, I give you money for membership and my membership gives me certain entitlements. Maybe it’s use of the fitness equipment, steep travel discounts, prestige, special service upgrades, access to events, etc. I join and I get something in return for me. Once the “member” hands over the payment, he or she need only sit back and enjoy the benefits of membership.

Becoming a member of PCB is not such a clear-cut transaction for a few reasons. First, PCB is a peer-driven, volunteer organization. Contrary to popular belief, its success does not depend on how many people “sign up,” but rather how many people are engaged in doing the work of the organization. In this peer-focused organization, the point is not on the immediate benefits to me, but on the long-term benefits for we, the community of people who are blind. When I commit myself to the good of the whole, I benefit too. The issue is further complicated because the Council sends the opposite message by continuing to charge a fee as proof of commitment to the cause. (This will be explored in my next article.) That annual “membership” fee can trigger a Pavlovian response, “I give you money, you give me something in return for the next year while I sit here and do nothing.”

I believe we can begin to change the message and the perception about being involved with the council if all of us more heartily adopt the concept of PCB as a peer network. Our purpose is to be peers with vision loss working together to promote independence and opportunity for all people with vision impairment; not members sitting stagnantly by waiting to enjoy the rewards of another’s work. Let’s get beyond that member “me” mentality by faithfully calling ourselves peers instead of members. Peers and people both start with “p”. Peers are representative of and work for all people with vision loss. Peers come to the organization with common experiences, work together to achieve shared goals, and mutually benefit from their successes.

Personally, I find being a peer much more rewarding than being a member. I didn’t recognize this until a few years ago, when a young professional woman who had been a member for about a year asked me why I am a member of the council. Specifically, she wanted to know what I get out of it? At the time I was truly taken aback by her question. I had never thought about my membership in terms of what I get out of it. I joined the council not to get something out of it, but rather to give something to it—my support, my service, my ideas, my voice, etc. While I have certainly reaped the benefits of membership such as learning about new blindness products, meeting new people, building my skillset, and connecting with mentors; my purpose for being involved with the council has always been mission-driven. I came to the council knowing there was work to be done both among and for others who are blind and visually impaired, and I jumped in where help was needed. Nearly fifteen years later, it’s amazing to look back and reflect on the impact my volunteer work has made.

I guess I’ve always looked at my involvement in the council much as JFK asked us to look at our citizenship in his 1961 inaugural speech. “And so, my fellow Americans: ask not what your country can do for you—ask what you can do for your country.” It’s never been about me. It’s always been about us.

PCB Conference Update

By Tom Burgunder, Conference Coordinator

The Pennsylvania Council of the Blind will hold its annual conference at the Crowne Plaza Hotel in  Harrisburg from October 17 through October 20, 2019. The  location of this year's conference suggests more people may  attend. You are encouraged to make your hotel reservations and travel plans sooner rather than later. (See below for hotel  reservation information.)

The planning committee has been meeting since January to develop a conference itinerary. A request for presentation proposals has  been sent to the membership and blindness organizations. At the time of this writing, one response has been  received which includes a general session presentation and a  table in the exhibit area.

A collaborative all-day session with the Bureau of Blindness and Visual Services’ Harrisburg office is being discussed  for Thursday October 17. The Board meeting will occur that afternoon. The first general session will open later that  evening. Some form of entertainment will follow both the Thursday general session and the Saturday evening banquet.

Breakout learning sessions are being discussed for the Friday afternoon  time block. Bring your cash or credit cards for the Friday evening auction. The likely exhibits will also be all-day Friday.

General Session programming will be scheduled for Saturday morning  followed by our business meeting in the afternoon. The day will conclude with a pre-banquet cocktail hour, the banquet, and entertainment.

Sunday will begin with a plated breakfast followed by a short meeting.

Regarding hotel reservations, the hotel advises as follows: Guests can call us directly at 717-234-5021 and reference the PA Council of the Blind or block code PCB to reserve their rooms. The group rates include singles (1 King) at a rate of $94 and Doubles (2 Queens) at a rate of $104. Your block includes the nights of October 16, 2019 through October 19, 2019. These rates do not include applicable tax.

Keep October 17-20 in mind and plan to attend this year's  conference.

An Explosion of News

By Mary Ann Grignon, Membership Coordinator

With spring on its way, the Membership Development Team seems to have renewed energy and vigor resulting in great new ideas for engaging our members.

First, let me thank all those who completed the “Getting to Know You Survey” and were entered to win a $50 visa gift card. Our lucky winners of that contest were Joanne Hollinger, Rodger Simmons and William Grigsby. Congratulations!

As always, we are hosting fun and informative discussion calls. What makes them so much fun you ask?  You’ll have to join us to find out. We collect ideas from you, our members, to touch upon those subjects you want to talk about.

Also, did you know that PCB has formed a new chapter?  That’s right, we now have PA Guide Dog Users  and Supporters (PAGDUS). If you would like to join the group, either because you are a guide dog user or you support them in some way, simply contact the PCB office to request an invitation to be added to the PAGDUS listserv or to learn about meetings and discussion topics. If you are looking for a primary chapter, dues are just $12. If you already belong to another chapter but want to join PAGDUS as well, then just pay $2 to the PCB office and you’re in.

Don’t stop reading yet, if you do, you’ll miss out on some new opportunities!

Let’s talk about first-timer scholarships for attending our PCB Conference and Convention. We will once again give away a  scholarship to a PCB member who has never been to a conference, an adjustment to blindness scholarship to anyone who both has never been to a conference and who is adjusting to new vision loss and 3 student scholarships as well. As in years past, all applications for these opportunities need to be completed by September 15. You need only write to me at maryanna0407@gmail.com with a brief bio telling me who you are and how you would benefit from attendance at our state conference and convention.

Now that’s all familiar to you but there is a new twist for this year’s conference. So, if you are a student, plan on being a student by the fall or know someone who is or will be a student, then keep reading!

This year, PCB’s board of directors has established a $500 Student Merit Award to be presented at our annual conference. So, in addition to receiving a conference scholarship, one lucky student will also win the $500 prize. Stay tuned for further details on how to enter as a contender for this opportunity.

Now, for something else brand new!  The membership team would like to hear from members who are entrepreneurs. Whether you have a home-based business, teach tech stuff, are a vendor, or anything at all, we would like to know more about you and your business. We have a plethora of ideas for networking and maybe even promoting your business among our members and beyond. For one thing, we are interested in creating a directory of businesses run by our members. Would you be willing to share your knowledge about creating an entrepreneurial opportunity, then maybe you would consider hosting a discussion call? If you would like to share your story or your business information, please contact me at maryanna0407@gmail.com.

Finally, I want to remind everyone that your participation in completing the “Getting to Know you Survey” helps us to offer opportunities that meet your needs and serve your interests. If you haven’t completed yours yet, it’s not too late to do so.

Thanks to my team for their hard work: Nan Scott; Rosemary Martin; George Holliday; Cathy Long; Mike Gravitt, our secretary; William Grignon and of course our president, Sue Lichtenfels.

Adventures and Thrills

Monday, April 1, 2019 at 7:30 PM

 What better way to celebrate April Fool’s Day than discussing the most thrilling or adventurous thing you’ve ever done with the PCB membership team. Have you driven a car or piloted a plane? Come share the craziest thing you’ve ever done, and the advocacy involved as a person living with vision loss. If you’re not an adventure seeker, come listen and live vicariously through others. No tricks here, just stories of daring adventures and thrills!

Call: 605-475-4715 or 844-844-0414 toll-free.

Passcode: 815419#

2019 FUND DEVELOPMENT ACTIVITIES

By George S. Holliday, Fund Development Coordinator

Spring will be here soon, and the team is gearing up for several activities for 2019. On behalf of the Fund Development Team, I want to thank Tony Swartz for his hard work for PCB. As of January 1, 2019, Mary Ann Grignon will be chairing the PCB Auction subcommittee, and Tony will act as an advisor. Be sure to read Mary Ann’s article about this year’s auction which follows this article.

For the past two years, the Fund Development Team conducted a Monthly Monetary Support (MMS) fundraising contest. It was successful for each year, so, the committee will continue the contest this year. Details of the 2019 contest are being finalized and will be posted soon. Results of the pledges made in the first year of the contest boosted PCB’s MMS contributions over $2,000 in 2018.

Both PCB and ACB win every time someone enters the MMS program. On behalf of the PCB Fund Development Team I thank you for your participation. Contest winners from our most recent MMS drive were: $100 first prize to Mary Ann Grignon, and $50 second prize to Chris & Doug Hunsinger.

The weeks are counting down until the beginning of the PCB Six-month Calendar Raffle. Do you have your raffle tickets? If not, PCB Chapter Presidents and others can still request tickets to sell from Christina in the PCB office. If you would like to purchase tickets, mail a check with details in the memo field to the PCB office, or call and purchase tickets via credit card.

The raffle runs between April 1 and September 30, 2019. Ticket price is $20 and includes all 183 days of the raffle. Winners are based on the PA Lottery 7:00 PM Daily Number (First Draw Only)

Winning days and amounts are:

Holidays on 4/21, 5/12, 5/27, 6/16, 7/4, 9/2 receive $125.

1st and 15th of the month received $75.

All other days are $30.

To acquire tickets, contact the PCB office at 717-920-9999 or toll-free at 877-617-7407, or email pcboffice@pcb1.org. Good Luck! And thanks in advance for your support of PCB.

The Fund Development Team is working on several additional projects, such as the Room-Rate Fund, Loving Touch Connection promotion, and development of the Cross Four game. You will hear about these projects and more in future editions of The PCB Advocate and the list-servs.

Also, if you have any suggestions for the team, or if you would like to join the team, you can contact me at george.holliday@comcast.net or 215-796-9813.

Going Once, Going Twice, Gone!

By Mary Ann Grignon, Auction Coordinator

If those words trigger a knee-jerk response to yell out a dollar amount, then you’ve probably attended a PCB live auction at one of our annual state conferences.

It’s never too early to begin thinking about a contribution to our exciting live auction, whether it is an item you donate personally or something donated by your chapter. I urge you to discuss auction donations at your next chapter meeting. In addition, please ask area businesses to consider donating to the PCB live auction. This year the auction is being held on Friday, October 18.

If you’re wondering what kinds of items are appropriate contributions the list is pretty endless. Of course, items specifically designed for those with vision loss are welcome but so are baked goods, jewelry items, hand crafted items, liquor, sports memorabilia, theater tickets, travel vouchers and all manner of bath and body items. Remember that food baskets and liquid refreshment always keep the bidding lively.

While we have no limit with regard to how much an item is worth, and while we will assign an appropriate starting bid to each item, I urge you to keep in mind that your donation may not be sold for its listed value. Your donation will always be appreciated and will contribute to the overall success of

this fun and lively fund raiser.

Stay tuned on the PCB-L for some suggestions as to items for consideration and the vendors from which to purchase such items.

# Latest News from the AccessiDocs Project

This year PCB's AccessiDocs project will offer another free gift of accessibility to PCB members, but more about that in a moment.

Are you interested in obtaining an audio Daisy3 recording of your favorite sports team's schedule? Perhaps you don't read braille or have access to your team's online schedule. If so, AccessiDocs can develop and mail to you a navigable recording of your favorite team's schedule. For the price of $3.50 which covers the combined cost of a thumb drive and small administrative charge, PCB will send you a thumb drive which can be played on your NLS player or copied to your preferred digital player. As an example, a baseball schedule can be navigated by month within the season at level 1, and by series within the month at level two. Football schedules include all the teams in your favorite team's division, with each team at level 1 and individual games at level 2. If you would be interested in obtaining a schedule, please contact the PCB office at 877-617-7407 to place your order.

Remember the mission of the PCB AccessiDocs project; if there is a public document, service guide, brochure, or handbook from an agency, government entity, or medical facility which you need to access, the AccessiDocs project can provide you with a navigable accessible audio copy. Please refer the creator of the document to the project by sending an email inquiry to: accessidocs@pcb1.org or have them visit [accessidocs.com](http://www.accessidocs.com) for more information.

Now about that gift: many of you are familiar with BlindAlive, Eyes-Free Fitness, a small business which has created a series of audio programs allowing the listener to stretch, strengthen, condition, and tone the body, all without the benefit of eyesight. Mel Scott, creator of BlindAlive, has graciously permitted PCB's AccessiDocs project to assemble the entire BlindAlive series of programs into a Daisy3 book for download by the membership of PCB. To download the BlindAlive Daisy3 book, members should visit pcb1.org/accessidocs. Look for

the download by mid-May.

Knowledge, Creativity, Belief

By Nancy Scott, KCB Member

The Keystone Council of the Blind (KCB) is a statewide telephone chapter of the Pennsylvania Council of the Blind. KCB meets the third Saturday of each month at 11 a.m. Usually, we hold a brief business meeting followed by a speaker or group discussion. Telephone meetings are slightly over an hour in length.

Have you ever considered what would happen if you were unable to tell an EMT or doctor that you couldn't track light with your eyes? How would you convey medical information that would make a difference in your diagnosis if you couldn't speak? At a meeting last

fall, Lisa Salinger talked about wearable and fileable medical information usually displayed on a bracelet or necklace. There was also discussion about Smart 9-1-1 which is available in some Pennsylvania counties.

Would you like to own a talking Power Bank? Or a sturdy backpack? Or a cane whose tip gives off enough light for people to see you at night? At December's meeting, we heard about guide lights and gadgets where we were tempted by many products and special pricing.

In January, we assigned chapter committees and talked about Netflix and Amazon Echo set-up and accessibility. The Echo Dot is still very inexpensive.

This year, KCB hopes to be over 20 members strong. Our current officers are: President, Mary Ann Moore (formerly Cowfer); Vice President, Lisa Salinger; Secretary, Lynn Shields; and Treasurer, Joe Fagnani. KCB annual dues are $12 which includes membership in both PCB and ACB. You can also join us as a secondary chapter choice for $2 per year, provided you are already a Pennsylvania Council of the Blind member.

Since we're on the phone, you don't have to travel or dress up. I often attend KCB meetings in bedroom slippers.

We are planning a meeting to introduce new members and catch up on the happenings of current members. We're also discussing future chapter projects.

Keystone Council of the Blind members have knowledge to share and the creativity and belief to put that knowledge to use. We invite you to be part of our journey.

For more information about how to visit or join KCB, contact the PCB office at 877-617-7407, President Moore at 814-215-0853, or Cathy Long at 717-732-5265.

LVCB is Blossoming this spring

By Liz Oleksa, LVCB President

The Lehigh Valley Council of the Blind (LVCB) is blossoming with new ideas and ways of getting more involved with our community this spring. As the times are changing in the world we live in, so are the needs and visions at LVCB. With a positive attitude and a welcoming group of people, our chapter continues to grow. Currently, LVCB is a bouquet of great minds, ideas and individuals from different generations. Our members range in age from 14 through 81, and we bring out the youthfulness and fun from within each of our members. All of our gatherings, activities and meetings are accompanied by new information, laughter and continually blooming friendships.

For the 2019 year, LVCB has decided to take a break from running our annual hot dog sale fundraiser, which has been taking place since 2003. With many of our members being actively involved with family, work, and other commitments, it has been difficult to staff the hot dog sale for the original 3 day stretch. Last year, we shortened our hot dog sale to 2 days instead of 3, yet still found it challenging to fill all our shifts. Even though we had a fine fundraising amount raised, we are looking into other ways to raise funds, without as much of a time commitment.

We will continue to sell Gertrude Hawke chocolate bars for $1 each throughout the year. For the past two years, this has been an excellent fundraiser for our chapter.

In addition to the Gertrude Hawke chocolate bars, LVCB plans to hold raffles throughout the year. (These include 50/50 raffles, items like hand-made Afghans, gift baskets/gift cards  donated by local businesses and more.)  LVCB will also be holding a fundraising evening at a local Panera Breads and More Restaurant. Panera offers this opportunity to non-profit organizations, where 20% of all sales from that evening go to the organization holding the event. This event will provide great friendship, promoting LVCB and PCB, good food and an easy way to get involved in the community.

LVCB is teaming up with the local Center for Independent Living and Center for Vision Loss for a demonstration of Pennsylvania's Certified Voting Systems Highlighting accessibility accommodations. On Thursday April 11th, at the Lehigh Valley Center for Independent Living, the vendors of state certified voting machine/systems will demonstrate the accessible features of their equipment. Over the next year, each county in Pennsylvania will be selecting a system to have in place by the 2020 presidential election. The demonstration, sponsored by the Lehigh Valley Center for Independent Living, the Center for Vision Loss, and the Lehigh Valley Council of the Blind will begin at 10:00 A.M. with a presentation from each of the vendors discussing the accessibility features of their system. The remainder of the day, attendees will circulate among each of the vendor stations and have the opportunity for a hands-on demonstration to judge for themselves the quality of accessibility of each of the systems. While all individuals with a disability are invited to attend, as are family members and friends, a registration is requested. To register or for further information, please contact Debbie Rozear, debbierozear@lvcil.org, 610-770-9781 ext. 124, or Tony Swartz, tbswartz@ptd.net, 610-799-4565. Please register by Monday April 8th. The demonstration event will be held in the Operation Overcome room on the second floor of the Center. Attendees are asked to arrive no later than 9:50 A.M. The Center for Independent Living is located at 713 N. 13th Street Allentown, PA 18102.

LVCB also continues to share information with the world through our Facebook page. Our page can be found by searching “lvcb1993” or “Lehigh Valley Council of the Blind LVCB”. We share all different types of information relating to vision loss, blindness and new technologies involving blind or visually impaired persons. Please check us out and like our page!

On Sunday evenings, the “Blind and Beyond” radio show, out of Orlando, FL, airs from 7:00 pm. to 9:00 p.m. EST. The show has guest speakers that call in and discuss various topics about blindness or vision loss. On Sunday, March 3, 2019, LVCB President, Liz Oleksa was a guest on the show to talk about LVCB, PCB, and over-coming obstacles in life with a positive attitude and determination. You can tune in live through their website or on your smart speaker. Just say: “Alexa, play WOKB 1680AM”. Liz was a guest speaker about 18 months ago, and was invited back to share more about LVCB.

AN Open Invitation to Humans and Guide Dogs

By Rose Martin, PAGDUS President

As the last snowflakes fall (hopefully) and spring awakens, Pennsylvania Guide Dog Users and Supporters (PAGDUS) is bounding into the new year. As a newly formed chapter of PCB, we wanted to extend a rousing welcome and open invitation for humans and guide dogs alike. Our membership is not only open to guide dog users, but those who support or are interested in guide dogs. We also welcome all dogs and humans, not just those living in Pennsylvania.

Our chapter meets on the second Wednesday of each even month at 7 or 7:30 p.m. EST, depending on the length of business and discussion topics. We will conduct business to start each meeting, then lead into the discussion. Those who are not members of PAGDUS are invited to call in for the discussion portion of our meetings. Our first meeting of 2019 included a lively discussion centered around traveling with a guide dog in the winter, as well as grooming tips and tricks. Future discussion topics we are exploring include, but are not limited to: how to know if a guide dog might be right for you, handling dog attacks, resources for dealing with dog emergencies such as injuries or illnesses, and educating business owners on the rights of service dogs and the difference between emotional support animals and service animals.

Our next meeting will be held on April 10, 2019 at 7:15 p.m. To join our conference calls, Dial: 641-715-0861 with Participant Pass code: 985255#. Be sure to subscribe to our chapter list serve to stay informed. Send a blank email to pagdus-l-subscribe@yahoogroups.com. You will instantly receive an email response to which you need only reply to confirm.

During our December meeting, the following officers were voted in by acclimation.

President: Rose Martin

Vice President: Mike Gravitt

Treasurer: MaryAnn Grignon

Recording Secretary: Rebecca Ilniski

Membership Secretary: Bob Lichtenfels

It’s never too late to join our chapter for 2019. Please send a check to the PCB office with “PAGDUS” in the memo field. For current members of PCB/ACB, our dues are $2. If you are not yet a member of ACB or PCB, dues are $12. We hope you will consider joining us, and we hope you’ll pass the word along to others you know who might be interested.

If you have suggestions for future discussions or projects you’d like us to consider, contact me anytime rosemary.martin92@gmail.com or 215-756-1624. We have many exciting ideas and projects for the future, and we’re just getting started! Just like our trusted guide dogs, our chapter will enjoy plenty of work and play. Now, forward!

Philadelphia Regional Chapter News

By John Luttenberger, PRC Corresponding Secretary

The past several months have been busy ones for PRC. At our June 2018 chapter meeting, we conducted a festive ceremony to present our two annual chapter awards. The Francis Williams Volunteer Service award was presented to Margaret (Maggie) Cicala, and the Mae Davidow Community Service Award was presented to Shirley M. Brotman. Each received a plaque in recognition of their service to the blindness community. Our guest speaker for the occasion was Ms. Karla McCaney, Executive Director and CEO of Associated Services for the Blind and Visually Impaired, where we've held our chapter meetings for many years. Ms. McCaney gave us a history of her career journey, and her plan of action for the future of ASB.

In October, six PRC members attended the 2018 PCB Conference and Convention in Pittsburgh. Our delegates were Bette Passanante-Rodriguez and Ed Facemyer, and three of our attendees took part in the post-banquet play, "Bag It Up."

As the year-end holiday season approaches each year, PRC selects a charity to which individual members and our chapter as a whole can make a financial contribution. For 2018, we chose, for the second consecutive year, The Career Wardrobe, an organization which helps their clients obtain gainful employment by providing them, at no charge, with suitable business attire to wear to job interviews, as well as with other supportive services.

At our November 2018 chapter meeting, we elected officers for the 2019-2020 term. They are: President, Shirley Brotman; Vice President, Ethel Siegel; Recording Secretary, Ed Facemyer; Corresponding Secretary, John Luttenberger; Treasurer, John Anderson; and Assistant Treasurer, Daisy Morgan.

As the year-end holiday season commenced, we were all saddened to learn of the passing of our president, The Rev. Dr. Patricia A. Russell, on November 23, who was completing her four years in office.

On December 8, the day of the Army-Navy football game here in Philadelphia, 15 chapter members attended our annual holiday breakfast at a favorite restaurant; it was enjoyed by all.

At our January 2019 chapter meeting, President Brotman led a memorial for former president Patricia A. Russell. We shared fond memories of Pat, and, upon conclusion of members' reminiscences, Diane Davis delivered a eulogy focusing on the many seasons of life, with the ultimate season for us all being death. She finished with the reading of a poem entitled “After the Tears.” Vivian Williams brought the ceremony to a close by singing “The Lord’s Prayer.” We then welcomed a guest speaker from our 2018 holiday charity, The Career Wardrobe, who brought us up-to-date on their activities this past year, and answered questions from the members. Following the talk, we presented them with our 2018 holiday donations collected from members, topped off with some funds from our Treasury. Observing that former president Patricia A. Russell believed that charity should be an essential component of our chapter makeup, we voted to establish an award in Pat's memory, which will accompany all future chapter donations to charities.

We look forward to a productive 2019.

Visual Hallucinations and Vision Loss

By Jule Ann Lieberman CLVT/CATIS and the Vision Loss Resource Team

“I was afraid to tell my doctor that I was seeing things that were not really there,” states a woman in her 70’s. She adds, “No one believed me, they assumed I was having a mental breakdown of sorts.” Her experience although uncommon in the general population was not a sign of mental illness, but rather a condition that is frequently misunderstood by persons experiencing vision loss, their loved ones and the medical community.

Charles Bonet Syndrome (CBS) causes visual hallucinations as a result of sudden onset vision loss and can occur at any age; however, it is observed most often with persons who lose their vision later in life. Some research suggests that 1 out of 5 persons who experience vision loss from macular degeneration, cataracts, glaucoma and diabetic retinopathy may experience these visual hallucinations.

This experience can be quite confusing, frightening and can lead to anxiety. With older adults, the hesitance of explaining these images can stem from being afraid of a diagnosis of dementia or another mental illness. Fear of describing these experiences can increase isolation and anxiety which can lead to multiple poor health outcomes.

“I was told that I had macular degeneration and that nothing can be done and just to stop complaining, crying and being depressed and go on with my life.” This is frequently the experience of those who speak up to medical professionals about their visual hallucinations.

Charles Bonet, a Swiss philosopher and writer, first observed this condition with his grandfather over 250 years ago. Images of repetitive patterns, birds and animals that were not really there were reported by his grandfather. Even though CBS has been around more than 250 years, many including the medical community fail to recognize this as a possible result of vision loss to this day.

What may be “going on” is that the brain is trying to fill the void where the eye provided vision previously. The eye is not the single component of vision, the brain interprets the signals sent from the eye and through a process of neuro transmissions along the visual pathway to the visual cortex where our “super computer” known as our brain incorporates these signals into what we perceive as sight. CBS perhaps is our brain’s way of filling in details we once were able to “see” and when the signal is lost or disturbed, substitutes appear.

These images can be as varied as the person who experiences them. A man in his 50’s found that the images of patterns and swirling lights were distracting and confusing until he recognized this as CBS. He has since begun incorporating these images in his artwork. Once the person realizes that it is not a mental health breakdown, coping with CBS can become easier. Sometimes these visual hallucinations go away on their own over time. They can re-occur when a person is fatigued, over-stressed, or if an infection or illness is present.

“I recently saw flowers on my cabinet, which were quite lovely, but not there,” states a woman. At the time, she had been experiencing an infection elsewhere in her body.

Others have expressed seeing faces, some disembodied and grotesque. Some recall seeing people in their homes who are not there and animals on their furniture or bedding. You can understand why being honest about these images would be frightening, not only for the person experiencing them, but loved ones as well. These experiences of visual hallucinations can lead to unnecessary hospitalizations for psychiatric observation and medication.

“I did spend some time on the psych ward as I did not understand that this was my eye condition causing these images. I thought maybe I was having a mental breakdown,” explained a 40-year-old who was not informed this could be a possible outcome of her sudden vision loss.

The difference when a person has visual hallucinations resulting from vision loss compared to a person who is having a psychotic episode is the person with vision loss recognizes that these images are not real whereas the person who is experiencing a mental crisis believes they are real, and they are accompanied by sound, smell or another sense.

There is no current medical treatment to stop CBS hallucinations; however, several coping strategies have been suggested. The images sometimes disappear if the person looks from left to right repeatedly for 15 to 30 seconds. Sometimes changing the lighting from dark to light or the reverse can make the images disappear. Taking up an activity such as watching TV, listening to music or reading a book can break the episodes of images. It is helpful to be able to explain that CBS is a result of your vision loss and not a mental illness and that you understand the hallucinations are temporary moments.

While an intern at a low-vision rehabilitation clinic, I met a few patients, who would tell me they were seeing something totally different than what was being enlarged on a magnifier. I questioned what they were seeing followed up with assurance that if they looked away or tried a few minutes later, the strange image would disappear. I smile when I think of a woman I worked with one day who had a delightful giggle while using a video magnifier. When I asked her what was so funny, she replied “I see little pigs.” I asked her if she liked little pigs, and she replied “Yes, but I really don’t want them to visit me right now.” We both laughed and the little pigs disappeared. She was comfortable in the realization that she had some control that if she gave it a minute or two the real images would return, and little pigs would play another time.

Please share this description of Charles Bonet Syndrome with your friends, families, and most importantly, your medical professionals as it just may save another person from anxiety and medical complications.

For more information on Charles Bonet Syndrome and additional stories of those experiencing CBS, please visit the Royal National Institute for the Blind: tinyurl.com/rnib-cbs or visit

tinyurl.com/moran-cbs to hear an interview with a social worker from the University of Utah Moran Eye Clinic.

I truly appreciate the brave volunteers who shared their experiences with me so that together we can educate and help others who are experiencing vision loss.

# My Journey toward Winning Friends and Influencing Others

**by Kelsey Nicolay**

As a college graduate with a degree in communication, I thought I was prepared for the workplace. Over a year out and still unemployed, I decided to listen to the encouragement of my cousin, who is a training consultant for Dale Carnegie, to go through their program. He told me that even though I had solid communication skills, I would still benefit from the course. It was a difficult decision, partly because I would have to depend on my family to transport me. After much thought, my dad and I decided that I should go through the program since I would acquire skills to prepare me to handle the stress and challenges of the workplace. In addition, the course served as an opportunity to network with the other participants in order to help me gain employment.

Prior to the talk with my cousin, I did not know much about the program. I knew that it had something to do with public speaking. At first, the staff felt they would be comfortable having me in class. “I can handle it,” said Elaine Dwyer, Dale Carnegie instructor, when informed by my cousin, a consultant for the program, that I would be enrolling in her course. Due to company policy, I was not given the name of my instructor, so I was not able to communicate with her ahead of time. The training consultant had to facilitate the entire enrollment process, including the initial discussion with the trainer. I felt more confident knowing my instructor would be able to accommodate my learning needs.

The first class was an orientation. The participants were introduced to the Dale Carnegie program, the areas of instruction, etc. Students were also introduced to some basic skills such as self-introduction techniques. Each student was then asked to practice these skills in front of the class. My classmates were willing to help me move around when needed.

During the first few classes, the students were introduced to fundamental communication skills such as name recognition, conversation starting, etc. The majority of this instruction was oral; therefore, all participants were expected to memorize the sequences or sayings without having them written down. However, at times a participant manual was used. I was able to obtain an electronic copy which I could pull up in class as needed. I was able to locate the other books on Bookshare, so I could read them independently between classes. At times when materials were not available electronically, I asked a family member to serve as a reader.

As the course progressed, there were some aspects which presented some challenges. For example, during one class, the instructor made up actions to go with a story in the book with which the students were asked to become familiar. The purpose of adding the actions was to help students add enthusiasm to their communication. Neither I nor the instructor considered how I would participate. Therefore, she asked one of the graduate assistants to try to describe what she was doing, but the graduate assistant could not describe the actions fast enough. Once the class learned the story with the actions, the students were asked to perform it in small groups. I did not do the actions. Instead, I was able to participate by helping to recite the words. “I realized I should have followed up with you,” Ms. Dwyer said after class that night. From this experience, we learned that it is important to anticipate challenges and plan accordingly.

During a later class, the students were asked to learn several silly skits to demonstrate being flexible with change. This time, the instructor and I talked about the best way to handle the situation. We both agreed that having me work with another person would be the best way for me to participate fully. The person I worked with verbally described what the instructor was doing while she was demonstrating the skit to the class. When the class was learning the skit, my partner would physically guide me through the routine. Once again, the class performed the skit in small groups. My partner helped me perform my assigned skit with my group. I felt more comfortable with this method since I could feel what the motions felt like.

As part of the course, each participant was required to give a weekly talk. The talks focused on gaining cooperation with others, demonstrating leadership, and enhancing relationships. During my speeches, I focused on dealing with the vocational rehabilitation agency and how I applied the principles learned in class to help me get the service I need. My classmates were not familiar with the system, but after listening to my talks, they had a better understanding of some of the difficulties I face. Although I had some difficulties in some areas, I was much more comfortable in other areas, particularly learning things by rote. For example, during one class period, the instructor wrote a saying on the board. I asked my neighbor what she was writing, and she quietly whispered it to me. The instructor went through the saying out loud, but having my neighbor whisper it to me ahead of time helped to solidify it in my memory. Therefore, it was easier to repeat the saying individually when the students were asked to do so later in the class period.

Before I knew it, it was graduation night, a night in which all our accomplishments would be recognized. Each student was required to give a final talk in order to receive his or her certificate. Prior to each participant’s speech, the instructor talked briefly about each participant, mentioning a highlight from his or her talk. I was a little nervous at first, but when it was my turn to speak, I stood up and confidently gave my speech. When I finished speaking, my family came up to present me my certificate as the other participants’ families had done. In the end, my family and I decided that the process was worth it, even though they had to drive me there and back every week. My advice to readers is that if a Dale Carnegie class is offered in your area, do not hesitate to participate. The skills you learn will help you in every aspect of life.

LTC Special Promotion on Treat Jars

Loving Touch Connection® (LTC) offers braille and art on glassware, gifts and products for people who are blind and visually impaired. Special promotions on featured items will be available to PCB peers and supporters throughout the year. Check out the following special through April 15, 2019.

* Pet Treat Jars - Special promotion price $26.00 (reg. price $28.00)- Beautiful accent for your kitchen counter and have your pets treats easily accessible.
* Paw Prints with raised outline, all around the jar. Choice of any color of paw prints. Please request color when ordering.
* 1 Qt. jar with lid. Lid has rubber seal to keep treats fresh.
* Raised braille word such as “treats” or dog’s name can be added to the lid for customization.
* 10% of sales goes directly to PCB.

Order your treat jar today at this special price by calling 610-657-9869 or emailing lovingtouchconnection@gmail.com.

Browse the complete collection of Loving Touch Connection® products by entering the online store through: [LovingTouchConnection.com](http://LovingTouchConnection.com) to be sure PCB benefits from all your purchases.

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PCB- A Peer Network for All Impacted by Vision Loss

Getting to Know You Survey

Fields with \* are strongly requested.

 Name\*:

 Birth Date:

What is your current age range\*: (please check one)

\_\_\_\_ Over 65

\_\_\_\_ 51-65

\_\_\_\_ 31-50

\_\_\_\_ 18-30

\_\_\_\_ Under 18

Street Address\*:

City/State/Zip\*:

County\*:

Phone #1\*:

Phone #2:

Email:

Please note: All peers will be automatically added to PCB’s email distribution list. Announcements of events, opportunities, and resources are sent out 2 to 3 times each month. For peers without email access, PCB posts monthly updates to the PCB Information Line, available by calling 773-572-6314.

Preferred Format of Material\*: (please check one)

\_\_\_Braille \_\_\_Large Print

\_\_\_Email \_\_\_Audio/NLS Cartridge

Are you a person with vision loss or blindness?\*

\_\_\_\_YES \_\_\_NO

If yes, how long have you experienced vision loss/blindness? (Please check one.)

\_\_\_\_ Since birth

\_\_\_\_ More than 10 years

\_\_\_\_ 5 to 10 years

\_\_\_\_ 2 to 5 years

\_\_\_\_ Less than 2 years

If you are not a person with vision loss, how are you impacted by vision loss?

\_\_\_Family member \_\_\_Friend

\_\_\_Community member \_\_\_Professional

\_\_\_Colleague

If you wish to tell us about any disabilities other than vision loss or blindness, please do so here:

Select your annual network membership type\*:

\_\_\_Individual Adult At-Large $10

\_\_\_Individual Junior (under 18) $5

\_\_\_Chapter/Affiliate Member $TBD

\_\_\_Nonprofit Agency $20

\_\_\_Corporate/For-profit $60

Which of the following PCB offerings are of interest to you?\* (Check all that apply.)

\_\_\_AccessiDocs Conversion Service

\_\_\_American Council of the Blind

\_\_\_Annual Conference

\_\_\_Having/Being a Vision Loss Mentor

\_\_\_iDevices for Independence

\_\_\_Leadership and Volunteer Opportunities

\_\_\_Local Chapters

\_\_\_PCB-Chat Listserv

\_\_\_PCB Telephone Information Line

\_\_\_Public Awareness & Peer Outreach

\_\_\_Public Policy/Advocacy Projects

\_\_\_Quarterly Newsletter

\_\_\_TheReImage Campaign

\_\_\_Topical Discussion Calls

\_\_\_Vision Loss Resources

Are you interested in being listed in a database of individuals who provide peer support to others impacted by vision loss? Please note, your name, email and telephone information will be shared with individuals who contact the PCB office seeking peer guidance.

\_\_\_Yes \_\_\_No

If yes, what type of experience or expertise might you be comfortable providing? (e.g. assistive technology, parenting, organizing, a specific occupation, language fluency, etc.)

Which of the following topical areas are of interest to you? (Check all that apply.)

\_\_\_Accessible Products/Devices

\_\_\_Adjusting to vision loss

\_\_\_Advocacy

\_\_\_Braille

\_\_\_Education

\_\_\_Employment

\_\_\_Guide Dogs

\_\_\_Health & Fitness

\_\_\_Hobbies

\_\_\_Home Management

\_\_\_Parenting

\_\_\_Personal Development

\_\_\_Sports

\_\_\_Social Media

\_\_\_Technology

\_\_\_Transitioning to Adulthood

\_\_\_Travel

\_\_\_Other (Please list.)

If you are seeking vision loss resources, please tell us more about your needs so we can best offer assistance.

Please note PCB project coordinators will contact you to provide or gather additional information based on your responses to all questions.

Free Matter for the Blind

Or Handicapped

(Handle as 1st class Mail)

Domestic Mail Manual Sec. 135.7

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PA COUNCIL OF THE BLIND

931 N FRONT STREET

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LARGE TYPE EDITION