

THE LILA FREE PRESS

Summer 2012

A publication of Lane Independent Living Alliance
Empowering People with Disabilities
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FREE TO ALL

Produced by the Board of Directors Newsletter Staff; Bonnie, Bruce, D.K., and Diane.

News from the Executive Director

After a long winter we can finally feeling the warmth of the sun, and see the flowers blooming. In May, LILA attended the third annual Bend Training – where four Independent Living (IL) staff had the chance to spend quality time with IL staff of the six other Oregon CILs. This training gives IL staff the opportunity to build collaborations with their counterparts around the state, learn new techniques, be involved in the development of best practices and hear from guest speakers. It's also nice to be in Bend for a few days!

LILA is now the Oregon affiliate for the US Business Leadership Network (USBLN), a national employer-led coalition dedicated to promoting opportunities that benefit businesses and people with disabilities. The USBLN focuses on low-cost, high impact solutions to help business attract and retain new employees and customers with disabilities. We will roll out our first

local meeting sometime over the summer. This is an exciting new step for LILA

Thanks to our consumers, volunteers, board of directors and staff. You make LILA what it is and we couldn't do it without you!

Be sure to join us for our Summer Bash/Pool Party 10th Anniversary celebration on August 12, Sunday at River road Emerald Park.

Sheila Thomas

The Gadget Corner: Funding Your Adaptive Equipment

By: Bruce Barney

Once you identify the equipment you're likely to need, your next step is to identify funding for it. If you're on disability, you may be able to get Medicare or Medicaid to fund it. Contact your primary care provider for information on how to proceed. There is likely to be a doctor's visit to evaluate the medical condition, and

evaluation by a therapist and perhaps a fitting by a technician. Once the equipment arrives, you may receive training on how to use it.

Work-Related

Workers Compensation

If you were injured on the job or on the way to/or from a job, you may qualify for Worker's Compensation. Contact your employer first then Worker's Compensation. They have their own system.

Oregon Vocational Rehabilitation Services (OVRs)

If your equipment is or could be required to perform a job function, OVRs may fund it. You would need a doctor's prescription for the equipment and any tests that documents the conditions. For example, if your vision is very low, and computer use is a job requirement, they will buy a computer monitor that comes up close to your face. If OVRs won't pay, your employer may, as part of the compliance with the ADA. Use the term "reasonable accommodation" when requesting the equipment. Employers have an escape clause in the ADA. They may say that any accommodation constitutes an "unreasonable hardship" on them. It's important to strategize thoughtfully about what you really need. If you work on the second floor of the building and you can't reach the elevator floor buttons, you don't necessarily need a standing wheelchair or remodel of the elevator. You may just need a stick.

Bathroom Equipment

Medicare and Medicaid do not pay for bathroom equipment (tub grab bars, toilet rails, bedside commode's, etc.). That equipment can be found at garage sales, estate sales, thrift stores, in your friend's garage, on Craig's list or at a Durable Medical Equipment (DME) dealer's. DME dealers often rent this equipment by the month. Be sure to get a demonstration on how the equipment works. Grab bars are sold at building supply stores. Installing them safely can be tricky so get advice from a carpenter or consult Gene Organ at LILA or the Eugene Building Department downstairs in the Atrium before attempting installation. The Community Development Block Grant (CDBG) Program in the Atrium building can also install them if you are low income. They also do home modifications – bathroom door widening, threshold jumpers, handrails, etc. The Atrium is located at 99 W. 10th Ave in Eugene.

Hearing Aids

OVRs will provide you one hearing aid if hearing is required for your job. You may have to pay for a hearing test yourself but many hearing aid businesses offer hearing tests for free, including Costco. The Lions Club's Audient program can help you get a hearing aid for half price if you have a low income. They may also be able to provide a used aid. Hear Now offers aids for \$50 if you have low income and have tried every other resource.

Glasses

The Lions Club offers free use frames from these they have collected but you must pay to have the lenses made yourself. There are many online sources for glasses like eyebuydirect.com. In town, Eyemart on Coburg Road has low prices. Be sure and ask when the glasses will be ready.

Buyers beware: it seems to be an increasingly common practice to promise the lenses sooner but after you have paid the money they tell you that we'll take two or three weeks before they arrive. If money is more important than effort, consider going back to get your money and go to another store. Sources of low cost eye exams are listed on the Internet. You must have a prescription before most glasses can be made for you. Low-cost reading glasses, however, are sold in bookstores, dollar stores, discount stores, and at pharmacies without a prescription requirement.

General

If you've tried every resource for your equipment needs and still can't find funding, the Blanche Fischer Foundation (www.bff.org) might be able to help you. If you decide to make something yourself or have something made, be very cautious. Homemade products can fall apart, be heavy, smelly funny, complicated, leak, rust, rot, etc. It may take a long time to get your device to work reliably. In general, if your design requires a canary, a frying pan, and a bowling ball—simplify. If you do get it to work, consider submitting it to workshopsolution.com or

abledata.com. Someone else may need it but can't work as hard as you have to design it. Design advice: it's hard to make things reliable and simple.

If you have questions Cora at LILA can't answer, leave them in the board members mailbox in the LILA office.

Resources

- Cora Jones at LILA 541-607-7020
- abledata.com or 800-227-0216
- workshopsolutions.com
- OVRS 541-686-7575
- Hear Now 1-800-648-4327
- Durable medical equipment dealers are listed in the Yellow Pages under "Medical Equipment & Supplies"

Farewell to LILA Co-founder Ellen Bombaro

By: Lynne Braverman McKinney

"Ellen passed away". Even over the phone I could tell my friend was fighting tears. Just the day before, I attended the 10th annual meeting of Lane Independent Living Alliance, also known as LILA. We talked fondly about Ellen and her role in its tumultuous beginnings.

In 1998 after a couple of false starts, Gwyneth Van Frank and I put together a meeting of people with disabilities who were interested in starting some kind of peer-based group. We hoped that a Center for Independent Living (CIL) would eventually evolve. Since I had worked at two CIL's, I was tasked with explaining that a CIL was a

peer-based, non-residential entity that met the requirements of the Federal Rehabilitation Act; to provide, at a minimum, peer counseling, advocacy, independent living skills training and information and referral for people with disabilities. Ellen, a heavy set blonde who wore a large bow in her hair and had a propensity for pink clothing, was among the most enthusiastic participants at our initial meetings. An active volunteer in Eugene, Ellen was a familiar sight, rolling around town in her electric chair, pink poncho flying.

We all agreed that we needed something in Eugene. Two previous attempts at starting a CIL had failed and it didn't take long to learn why. Our group was composed of long time activists with strong opinions and the ability to express them aggressively. To say we struggled over our diverse ideas would be putting it mildly. Interminable meetings at the Hilyard Center morphed into more lengthy meetings at Ellen's house where we shrank into a core group (after scaring away anyone unwilling to endure our fierce debates), then in her building's community room as we expanded again.

Ellen held us together. She helped us laugh at ourselves when we got too intense; made sure we had coffee and cookies at our marathon meetings and organized frequent get togethers. Bringing new members to our group was one of her specialties.

By the time LILA finally opened its doors in 2002, Ellen was our Board

Treasurer and Secretary. She was also the receptionist, office manager, organizer, and social director. In those early days people would wander into LILA and Ellen would find them something to do. Ellen used the savvy she had gained as a Craps Dealer in Las Vegas to make each person feel important and respected. She couldn't accept a staff position because she received a small pension from Nevada (she fell out of a cherry tree and became quadriplegic) and the State, in its wisdom, wouldn't allow her to work for pay. Even so, Ellen was at the front desk every day.

Ellen once told me that becoming a quad was the best thing that ever happened to her because she was freed from her abusive boyfriend. The physical aspects of her disability bothered her much less than the difficulties of staying independent with her level of disability. She was dependent on a caregiver (we call them personal assistants) for many of the activities of daily living. The funding for a personal care assistant was insufficient to allow for true freedom. Ellen's life was bound by the hours her assistants got her up in the morning and put her to bed at night. She was lucky to find long term employees who were usually reliable. Other people with disabilities often complain about the high turnover of personal assistants who receive minimum wage from the State In-Home Support System. Constant retraining of new employees is necessary and there is always the fear of being left without the necessary assistance. Many people on In-Home Support Service

find creative ways to supplement their assistant's pay from their meager benefits.

Ellen lost her independence after a long battle with the State of Nevada which refused to pay for her caregivers, insisting that she move to a much more expensive long-term care facility instead. The LILA community rallied around her and offered to advocate, but Ellen was exhausted from her struggles for independence and we reluctantly agreed to support her decision. She moved to a facility in Albany, then to Portland where she succumbed to an infection in February 2012.

Ellen's story is an integral part of LILA history and a justification for its existence. As long as people with disabilities are denied independence, CIL's like LILA will keep advocating for the empowerment, rights and freedom for people with disabilities. Ellen will be remembered as one of the great, unsung heroes of the local disability rights movement. She is a shining example of a person with a significant disability who helped empower and support others.

Training Your Dog

By: Bonnie Berman

Dog training is an individualized activity. You must approach it based on your temperament, your strengths, and those of your dog. In this article, I have some exercises within three categories:

1. Ambulatory for those who walk without aid.

2. Ambulatory which includes crutches, canes, walkers, walking sticks, etc.
3. Manual wheel chairs, power wheelchairs, and scooters.

If you use crutches to help you walk or a power chair for example, you will learn the best way for someone with crutches or other appliances to find the correct way for you and your dog to work together.

Dogs

Just as we are different from other people, so is your dog different from other dogs. Some are very intelligent, but difficult to train. Others are highly motivated to learn. This has nothing to do with your disability. Your dog is an individual and has breed-related characteristics. You can learn to train your dog no matter the breed, size, temperament, sex, or age. All dogs are trainable to some degree but some are easier than others and you will have to be creative to motivate your dog.

Attitude

In training your dog it is important to have the correct attitude, which is a positive attitude. Most important, never hit your dog. I can't stress this strongly enough. All it does is make your dog afraid of your hand and wary of you. You need your hands to always be symbols of love.

Slow is fast.

As I continue to train you as the dog handler, please remember that slow

is fast. These three little words will remind you that in dog training, it is important not to rush. But pushing your dog too hard, you will end up with you having a sloppy foundation. Dogs need time to absorb what you're teaching them. It might take hundreds of repetitions of just one exercise for them to really know it. If you practice four times a day, it may take nearly a month for your dog to have it down solidly. So, if you move on to sit-stay after one week, and down-stay the next week, you're probably going too fast.

This isn't a race. There is no prize for finishing all the exercises in the shortest amount of time. The reward is over the long-haul. You want your dog to work for you for many years. Take the time to develop the required solid foundation required for a lifetime of service.

For someone with a physical disability, slow and steady is the only way to go. Your disability may prevent you from making quick corrections. Traditional trainers will tell you that timing is everything, saying that you must make your corrections quickly so that the dog will understand or that you must give the food reward instantly so the dog makes the connection.

It may not be possible for you to do anything quickly. But consistency and patience is more important than timing. Consistency is a personal thing between you and your dog. Your dog will make the connection with the reward if you work as patiently as possible on each exercise. Most importantly, give

your dog the chance to really understand each step before you move on.

Spotlight on Staff **John Roberts: A Champion with a Heart of Gold**

By D.K. Stotler, LMFT, CADC III



John at Hayward Field, April 12, 2012
Photo by: Sandra dela Rosa

Achieving his personal best, whether as a LILA Peer Support Assistant or as a track and field athlete -- is more appealing to John Roberts than impressing others with his computer wizardry or, for that matter, by winning a gold medal.

In addition to his part-time position at the LILA Peer Support Club, where he specializes in computer applications and tech support, John relates that he has a "full-time job as an athlete" training for the 2012 U.S. Paralympic Track and Field Trials, which take place in Indianapolis later this summer.

And, as if those activities wouldn't exhaust the rest of us mere mortals, John, who majored in Human Services at Lane Community College, also juggles his busy schedule with two other part-time jobs at the City of Eugene Recreation Services, a position similar to his job at Peer Support Club, in which he teaches basic computer skills and works one-on-one with elders at the Campbell Senior Center.

So, how does he do it? "It's an up-at-dawn thing," he smiles.

Initially a volunteer member when he joined the LILA family last summer, John says he was quick to "step in whenever tech support was needed." A conversation with Program Coordinator Marsha Evans regarding the much need service of tech support at the Peer Support Club ultimately led to a job offer in late August.

Pointing out that he wears "many, many hats around here," John humbly rattles off a list of duties that include "picking up the slack when others are feeling overwhelmed." He especially likes being able to work with people from all walks of life.

"It's nice," he says, "to help people navigate their way through life and around the Internet, and to do whatever I can do to help them find basic services, such as transportation and housing."

An insightful and determined young man with an infectious and endearing grin, John is not one to

back away from a challenge. He acknowledges that some days are better than others at the Peer Support Club.

"When you work with people from different populations, your patience gets tested once in a while. Sometimes, the most basic task can be overwhelming for someone who struggles with whatever issue they're facing."

As for the challenges associated with wheelchair track and field competition, John says, "It's something I latched onto, and I wanted to see how far I could take it." He notes that he enjoys "training a lot more than competing, because training makes the competition so much easier."

Thus far, John has competed at the 2003 World Championship in New Zealand, and he was named to the U.S. Paralympic national team last year. He competes against other athletes with cerebral palsy, and set three national records when qualifying for the national team. "By a wide margin," he beams.

On April 20, 2012, John raced and qualified for the 2012 Oregon Relays Meet held at Hayward Field. John Roberts is headed to Indiana for the Paralympic Track Trials, which run from June 29 to July 1. Congratulations, John! We wish you all the best!

While the ultimate goal is to qualify for the U.S. Paralympics in London this August, John says, "I just want to do the best I can do." He explains

that “it’s a crap shoot; anybody can win on any given day. So, I’m realistic about it. I take tiny steps to make really small gains as the season goes on, because I don’t want to peak too soon.”

“This year is the hardest I’ve ever worked. The margin for error is very tiny, so I try to maximize my performance as much as possible by focusing on the fundamentals,” such as eating right, sleeping well and training rigorously. “Even to the point,” he says, “of making sure there’s enough air in my tires.”

Besides attending to the basics, how does John stay motivated and mentally focused during a competition? “I try to be as positive as possible, to give myself the confidence that, once I’m in the thick of it, I can go as fast as I can.” Although John grew up in a really athletic family, he says, there were few opportunities for people with disabilities in the small Midwestern town where he lived with his parents and older brother, a college athlete and a major inspiration for John’s athletic aspirations.

After moving to the Eugene area in 1994, John says he met several athletes, “who became my mentors, and I tried to learn as much as I could from them.” In addition, he watched his brother work really, really hard at sports, and was inspired by his ability to meet his goals by using his talents.

John has lived independently since age 21. “I can do most things,” he says, “just like anyone else. I try to

use athletics as a platform to promote athleticism through disabilities. A lot of athletes with cerebral palsy don’t get the recognition they deserve.”

“I’m trying to make the sport grow. I want to put up [race] times that, hopefully, some kid from a small town looks at and says, ‘I can do that, too.’”

“The greatest thing about the Paralympics is that, no matter what your disability, you can compete at your highest level. You can be the best cerebral palsy athlete, because standards are different for every disability. It’s more of a realistic playing field.”

Equally important, John says, is the opportunity “to meet lots of people who have disabilities who’ve been able to maximize their talents and abilities.”

We at LILA wish John the very best in his awesome pursuits.

Come One, Come All. LILA’s 10th Anniversary Celebration Summer Bash at River Road Emerald Park, 1400 Lake Drive on Sunday, August 12, 2012. 12:00 to 1:00 pm pool party, bring a towel. 1:00 to 3:00 pm picnic potluck. Will be located in the Pavilion #1. Potluck, BBQ, Fun and Games. All LILA Staff, board, volunteers, families, and supporters are welcome. The shelter is covered, large and accessible. Well-behaved dogs are welcome. Come celebrate with us.

Guidelines for Newsletter Articles

We welcome articles related to independent living written by local authors. List author, their credentials, how the article is related to the readers of the newsletter, the information you want to give, and where readers can go for further information. Please keep articles under 250 words.

Readers: Please submit articles by dropping them in the "Board of Director" inbox labeling them "attention: newsletter."

The newsletter staff reserves the right to edit and/or condense articles submitted.

Humor is always appreciated.

Congratulations to Roxie for making it on the Trillium CCO Community Advisory Council.

FREE Business Card Ad

Opportunity. Submit your business card for FREE inclusion in LILA's new business directory. E-mail to Hillary at hnelson@lilaoregon.org or mail to LILA with the caption "Newsletter Display Ad." We are especially interested improving information about disability resources and support.

A big thank you goes to Hillary Nelson of the LILA Staff for her expertise in putting this edition of the newsletter together. Well, done.

LILA is a cross-disability, consumer driven organization. Our goal is to help people with disabilities achieve as much choice, access, inclusion and independence as possible. We invite you to learn more about the many programs LILA offers and to consider becoming a voting member of LILA. Working together, we can break down societal barriers so that all people with disabilities are free to fulfill their potential.

This document is available in alternate formats (large print, Braille, electronic). To request, call LILA 541-607-7020.