

Disability Issues

Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.

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A Disabled Pilgrim

By Richard S. Hackel

Coincidentally I share a birthday and a disease with Lou Gehrig. Both of us were born on June 19th and both of us were diagnosed with a disabling neurological disease that robs muscles of electricity. Since August 2001 "Lou Gehrig's disease" has disabled my body such that I walk with the aid of a rolling walker, sleep with the assistance of a bipap machine, and use a scooter for excursions.

In June 2014 my wife and I will celebrate our 50th wedding anniversary. Before ALS we enjoyed traveling, so as an anniversary present we decided to take an interfaith trip to Israel which was organized through Israel Tour Connection ("ITC").

Before committing to our trip, I contacted ITC. "Will all of the hotel rooms be handicapped accessible?" "Will I be able to rent a portable scooter?" "Will they arrange for wheelchair access at the airport?" ITC answered all of my questions affirmatively.

On Sunday, April 27th we flew from Boston to New York and then from New York to Tel Aviv. Because of the

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Medical Marijuana: An Issue the Color of Smoke

By Kate Ryan

Medical marijuana may be one of the most divisive issues to hit the disability community in years. On the one hand, you have the fact that many major medical societies, including the American Medical Association, the National Multiple Sclerosis Society and the American Cancer Society are against it. On the other, you have the simple, undeniable stories of people who are in pain, and who say that medical marijuana is the only thing that helps with the pain. The only thing that both sides agree on is that people shouldn't have to be in pain. What they disagree on is treatments for that pain.

Regardless of personal opinion, it is the truth that in November, 2012, Massachusetts voters passed Ballot Question 3, "An Initiative Petition for a Law for Humanitarian Medical Use of Marijuana" with 63.3 % of people voting in favor of the bill. On January 1, 2013, this bill became law, allowing qualifying patients with certain defined medical conditions or debilitating symptoms to obtain and use marijuana for medicinal use. In the following months, the Department of Public Health, which was charged with overseeing medical marijuana in Massachusetts, listened to and obtained the opinions of many people and organizations in order to craft a set of regulations regarding the use of medical marijuana. They then showed the proposed regulations to the public and received more feedback, which was very mixed. Some people thought that the rules were too strict; others, too lax.

After many months of debate and discussion, the DPH adopted a final set of regulations on May 24, 2013. These regulations state that in order to obtain medical marijuana, a person must apply for and be granted a registration card for its usage. Conditions of



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A Disabled Pilgrim - *Con't from page 1*

pre-planning, upon presentation of my electronic ticket I was given a wheelchair and an attendant to assist me through security, through the terminals in NY, and onto the airplane.

After an 11½ hour overnight flight we arrived in Tel Aviv. Much to my disappointment the trusty walker that had been my "companion" for over 3 years was fatally damaged on the flight from NY and was no longer useable.

My wife and I immediately went to "Lost & Found" to report the damage. I explained that without the use of a walker I could not travel from bed to bathroom or walk even a few steps without its support. Fortunately they had another similar walker that they were able to lend me. I was indeed "lucky."

After retrieving our luggage we joined other tourists on the tour bus. Upon our arrival at our hotel in Tel Aviv the scooter was delivered. It was substantially like my scooter at home and it was portable enough to be collapsed and carried on the tour bus on our 12-day tour. It only required overnight recharging. At the hotel with the use of an electric plug converter I was able to plug in my bipap machine. The next day we were off to the north to visit the Roman port city of Caesarea, to Haifa, and then a Druze village. I was able to use the scooter to negotiate the narrow and hilly streets of the Druze village. With the assistance of fellow tour members I was able to join our group for a special Druze catered lunch. Later that day we arrived at our hotel on the shores of the Sea of Galilee/Lake Kinneret.

The next day included a boat ride on the Sea of Galilee, which required assis-

tance to lift my scooter from the dock onto the boat. The following day we visited the Golan Heights and then on Friday after a visit to Nazareth we were off to Jerusalem. On Friday night as the Sabbath approached we took part in evening services at the Western Wall. Jerusalem is quite hilly and the sidewalks are cobblestone so travel with the scooter was difficult, but with help from my fellow travelers I was able to manage.

We stayed in Jerusalem from Friday through the following Wednesday when the tour ended. Some sites were handicapped accessible and some sites were not. I was able to visit a synagogue for Saturday morning services, St. Georges Anglian Church for Sunday morning services, Yad Vashem (the Holocaust Memorial Museum), The Israel Museum, The Garden of Gethsemane, have lunch in



and tour the West Bank settlement of Tekoa, and even take a day trip to the Dead Sea and ascend Masada via cable car.

I was not able to visit the Mount of Olives, the Stations of the Cross, the old Jewish quarter in Jerusalem, or the Church of the Nativity in Bethlehem as the terrain is quite hilly and not handicapped accessible.

In all of our hotels the bathrooms were "handicapped accessible." Unfortunately, for me I could not take a shower without my wife's assistance because they did not have adequate grab bars. The handicapped shower was in a corner of the bathroom and consisted of an overhead and a hand-held shower. I had to hold onto a shelf or a small grab bar while my wife washed me and then hosed me down. I brought my rubber Crocs with me to avoid slipping on the wet floor.

On Sunday we returned home. Israel Tour Connection had arranged transport for us to the airport such that we were picked up at our hotel, taken to the airport, provided a wheelchair, and expedited through security.

We had a wonderful and memorable trip, which was made possible with time spent on pre-planning, assistance from my wife and other fellow travelers, use of a scooter, and a little bit of luck.

Richard S. Hackel is a 1965 graduate of Middlebury College and a 1968 graduate of Boston University School of Law. Richard practiced law in Boston, MA from 1968 to 2005, when he retired. In August 2001, Richard was diagnosed with ALS. Since diagnosis he has been a patient at Beth Israel Deaconess Medical Center.

Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital. Its main campus located in Boston, as well as Spaulding Rehabilitation Hospital Cape Cod, two long term care facilities Spaulding Hospital Cambridge and Spaulding Hospital North Shore and two skilled nursing facilities, as well as twenty three outpatient sites throughout Eastern Massachusetts. Spaulding is a teaching hospital of Harvard Medical School and the official rehabilitation hospital of the New England Patriots. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by *U.S. News and World Report* in its Best Hospitals survey with a #6 ranking in 2013. For more information, visit www.spauldingnetwork.org.

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From the Editor

Dear Readers,

I hope you are savoring the sweet taste of summer... fresh corn on the cob, sweet and juicy watermelon, refreshing iced tea, and tomatoes with basil plucked right from the garden. After this winter, I am delighting in going outdoors without worrying about how many layers to wear and where I can safely place my crutches without fear of slipping.

In this issue we bring you two articles related to drug usage. The first is an informative article with varying perspectives on the medical use of marijuana in Massachusetts that voters passed as a ballot question in November 2012. This law has significant impact for members of the disability community who are in pain and need relief. The second article shares research on the increased level of substance abuse for persons with disabilities. The statistics are surprising and sobering. Our intention is to educate and emphasize strategies for prevention and early intervention.

When I consider taking a vacation outside of the United States, my dreams of exploring far away lands is quickly inhibited by concerns about accessibility and "what if" scenarios. In the article "A Disabled Pilgrim," I found encouragement in hearing about one man's trip to Israel and how he navigated disability related challenges, creating a wonderful and memorable vacation for himself and his wife.

We also continue our open discussion on the taboo topic of sexuality. Our interview with Dr. Carol, Staff Sexologist at Good Vibrations, continues to share alternate ways to have satisfying sex. I often talk about people with disabilities having deeply honed skills of creativity and adaptability. Dr. Carol Queen is inviting us to apply these qualities to sexuality and consider a wider range of options than we may have previously considered. Her suggestions definitely stretch me beyond the boundaries of my comfort zone, and in doing so, opens up a new world of sexual possibilities! Maybe for you too?

Marianne DiBlasi, Editor

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getting the registration card include seeing a qualified doctor who certifies them as having a debilitating medical condition, submitting personal information such as name and address, and agreeing to not distribute, sell or give marijuana to anyone else but themselves. They can then obtain a 60-day supply from an approved facility.

Chandra Batra, of the Massachusetts Patient Advocacy Alliance, for one, is happy that medical marijuana has come to her state. She worked hard for the bill's passage, collecting signatures, speaking at the State House and attending events. She says that it is better than anything else she has tried in treating her fibromyalgia and chronic pain issues, and notes that she hasn't been bedridden in the 3 years she has been using it.

John Greene, of the Greenway Wellness Foundation, agrees. As an herbalist with many years of experience, he has seen marijuana successfully be used as a treatment for pain related to cancer, HIV, MS, and other diseases, as an appetite stimulant, as a mood booster, and to relieve anxiety. He hopes to open a medical marijuana dispensary in Cambridge, MA, by early to late fall of 2014, and anticipates providing it in tinctures, balms, flowers, patches and pills, among other forms. He notes few, if any, side effects.

Dr. Kevin Sabet, of Smart Approaches to Marijuana, could not disagree more. He says that medical marijuana has "nothing to do with the terminally ill, and everything to do with a way to smoke pot." He and other opponents, including the Massachusetts Medical Society, the American Cancer Society, and the National Multiple Sclerosis Society question why the state allowed the general voting public to make decisions about medicine, instead of going the regular route through clinical trials and doctor's recommendations. Dr. Sabet admits that marijuana does contain medical properties, "...but we don't need to go around the system, opium also has medical uses but we don't smoke it, we get morphine instead." Although

"We owe the sick and dying more, a regularized, standardized medicine."

— Dr. Kevin Sabet

John Kelly, of *Not Dead Yet*, assures this reporter that you quickly figure out which is the right dosage for you when you smoke it, and that it is easy to obtain from trusted sources. Dr. Sabet warns that consumers have absolutely no way of determining what exactly they are getting, and that cultivated medical marijuana often

contains high levels of pesticides and other non-organic substances. The one thing that everyone I talked to agreed on is that there is a desperate need for more research and development. There are not enough randomized, clinical studies and trials, just a lot of anecdotal evidence. More regulations and more testing of medical marijuana will ultimately make it only safer. There is hope; on June 4, the *New York Times* reported that New York State, along with a British company, is starting clinical trials of marijuana as medicine for children with uncontrollable seizures. The problem is, of course, that studies take too long, and people are in pain and need relief now. Dr. Sabet says, "We owe the sick and dying more, a regularized, standardized medicine." Hopefully, over time, both opponents and proponents will find that happy medium and marijuana will be researched and trialed enough to be accepted and available at your local drugstore, just like any other prescription.

Kate Ryan is a disability advocate who lives in Arlington.

This article was extensively researched and acknowledges that there is a lot more information out there than what is presented above.

For more information on the topic of Medical Marijuana, please visit the following websites:

DPH Medical Marijuana:

www.mass.gov/medicalmarijuana or call 617-624-5062

Massachusetts Patients Advocacy Alliance:

www.compassionforpatients.com

Smart Approaches to Marijuana: www.learnaboutsam.com

Substance Abuse in the Disability Community: Prevention is Key

By Raymond E. Glazier

Substance abuse is a major, widespread social problem with severe personal and social costs that affects persons with disabilities more than others. A body of previous research has found that general substance abuse is more common among persons with disabilities than among those without disabilities, and the effects are arguably even more detrimental for us. Substance abuse especially limits the potential productivity of affected persons with disabilities, because, as Li and Moore (2001) note in their study of disability and illicit drug use, "Compared to the general population, individuals with disabilities are more likely to encounter problems of personal adjustment and unemployment, as well as the experienced medical and health difficulties."

It seems self-evident that the widely documented negative physical and mental effects of substance abuse must further compromise the already impaired functional capacity of most persons with disabilities. Ryan Kling of Abt Associates (Cambridge) and I felt that these findings must be flukes. So we looked at a decade of survey self-reports of substance abuse by persons with and without disabilities to try to identify which substances persons with disabilities might be more prone to fall victim to, and to what degree, as well as the trends over time. We looked at admitted abuse for each substance in the month before the survey for working age adults ages 18 -64.

What we found really surprised and dismayed us. The prevalence of Overall Substance Abuse was level over time, at 40 percent for persons with disabilities, compared to just 34 percent for persons without disabilities, although there were changes over time in which substances were abused more. This composite measure included: use of street drugs, heavy cigarette smoking, alcohol abuse, and prescription drug abuse.

Over time, the admitted previous month substance abuse among persons with disabilities closely paralleled that of other persons, but at a statistically significant higher level, for each substance with only one exception: Persons with disabilities were less likely to report alcohol binge drinking, defined as 5 or more drinks at one sitting. These findings

from ten years of data from the confidential, anonymous National Survey on Drug Use and Health, took into account differences in gender, race/ethnicity, age group, education

level, income, and urban vs. rural residence. Trends over time were pretty much stable for both persons with and without disabilities, with the exception of decreases in cocaine use and recent dramatic increases in marijuana use and oxycodone abuse, although in recent years heroin has become cheaper than oxycodone and cut into the street market for this heavy duty prescription pain killer.

Psychologists have advanced various theories, trying to explain the higher levels of substance abuse among persons with disabilities: dulling the physical and psychological effects of disability, coping with the social stigma of disability, a sense of 'entitlement' to release from harsh realities, greater access to and reliance on prescription drugs, etc. Whatever the reason, the fact is that consumers, their peers, and their providers need to be vigilant and diligent in recognizing signs of substance abuse, intervening early, and identifying treatment options. Given the scarcity of accessible treatment programs and facilities, prevention is the key. The accompanying 'Top Ten Substance Abuse Scorecard' is important as a sort of checklist, showing key targets for prevention, identification, and intervention among consumers with disabilities and how much greater their likelihood for abuse is than for those without disabilities.

Top Ten Substances Abused More by Persons with Disabilities

Rank Order	Substance of Abuse	Greater Likelihood
1	Heroin	odds of 4.24
2	Methamphetamine	odds of 2.99
3	Oxycodone / OxyContin®	odds of 2.86
4	Sedatives	odds of 2.84
5	Cocaine (crack or powder)	odds of 2.27
6	Heavy Cigarette Smoking	odds of 1.92
7	Tranquilizers ('downers')	odds of 1.87
8	Analgesics (pain killers)*	odds of 1.77
9	Stimulants ('uppers')	odds of 1.74
10	Psychotherapeutic Drugs	odds of 1.72

* Other than Oxycodone / OxyContin®, analyzed separately.

Raymond E. Glazier, Ph.D., formerly of Abt Associates Inc. in Cambridge, is an SSDI beneficiary who returned to full-time employment in order to support himself and his family; now semi-retired, he is founder and Principal of disAbility Research Associates, LLC of Belmont, MA.





Ask Ms. Love

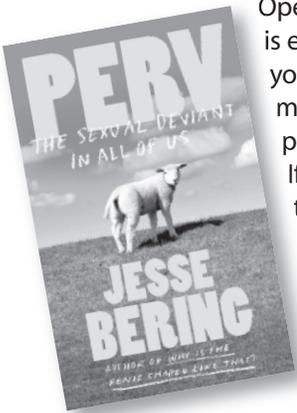


Dr. Carol Queen
Good Vibrations Staff
Sexologist & Historian

What follows is a continuation of Ms. Love's interview with Dr. Carol Queen, sex-positive retail store Good Vibrations' Staff Sexologist, and Kristen Cotter, manager of the Brookline, Massachusetts branch of Good Vibrations.

LOVE: Some readers have felt their children and grandchildren might know more about sex than they do, and they wonder what is "new" that they should know about sex.

QUEEN: In a way, there is nothing new under the sun, but access to information about sexuality and sexual variations is more available than ever before. It is in books, on the Internet, and on TV. The largest change is technology. It gets information, including erotic material, to people via laptop and smartphone, it adds value to sex toys, and it has changed the way many people meet and mingle.



Open discussion about sexual options is easier to find than when you were young, but no one is really doing much of anything that was never part of the sexuality spectrum.

If you want a good read about such things, check out Jesse Bering's book, *Perv: The Sexual Deviant in All of Us*. It is not for the faint of heart, but it is much more charming than you would guess at first glance.



Aging and Sexuality – Part 2

By Ms. Love

COTTER: Technology has also opened the doors to a deeper and more honest conversation about sex and sexuality. More and more people are moving away from the traditional ideas of gender roles, expectations, and "goal-oriented" sex. Of course, there is nothing wrong with keeping up with tradition, but sometimes people do not fit neatly into traditional gender roles or expectations and this might make them feel alienated, like they do not have a "place" where they feel comfortable expressing their sexuality or desires, or they do not feel like they live up to traditional expectations. When people do not feel comfortable in their own skin, it can affect their self-image, their self-esteem, their confidence, etc. It can snowball and become a much larger issue that can affect every aspect of their lives even if they do not realize it.

Technology is changing that. With technology, individuals can find communities or other individuals who may be experiencing similar feelings or seeking answers to questions or solutions to problems that just have not been researched, discussed or produced yet. A perfect example of this is older folks or people with different abilities seeking representation in porn or erotica. Why isn't it out there? Why is the selection so low when we all know that so very many people fall into this boat? The world is just now opening up to all these new ideas on body image and sexuality. It is not diminishing tradition, but it is supplying more options for those who are stepping up and looking for answers, representation or information that goes beyond traditional expectations.

For information on moving away from "goal-orientated" sex, please view Al Vernacchio's TED talk by visiting www.Ted.com and searching on "Sex Needs a New Metaphor"

More of this interview on aging and sexuality will appear in future columns by Ms. Love.

Good Vibrations' website is www.goodvibes.com, and the Brookline store can be reached at phone 617-264-4400. Older adults may ask for the senior citizen discount when they check out their purchases at the store.

The Love and Intimacy Corner welcomes questions and requests for topic areas from readers; please send all suggestions to DI.LoveandIntimacy@gmail.com

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The pathways are a combination of paved and finely crushed stone dust. There are also boardwalks and bridges. The terrain is considered accessible.

For more information, including a calendar of special events, visit www.friendsofalewifereservation.org

The Reservation is located at the end of the Minuteman Bike Path in Arlington. **Directions by MBTA:** Located at the Alewife station on the Red Line. **By Car:** Alewife Brook Parkway. Parking at Dilboy Field.



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Information Briefs - *Con't from page 7*

As I See It

Robert T. Branco has been blind since birth and has self-published two books that share his experiences and viewpoints on what it's like to be blind.

The book, *My Home Away From Home*, takes the reader along on his eight-year journey of living at Perkins School for the Blind from ages 12 – 19. Robert shares his perceptions of how significant changes in legislation and policies like “mainstreaming” affected his school experience. In remarkable detail, he also shares his daily living experiences such as, what it was like to live in the Perkins “cottages,” academics, extracurricular activities, and the inevitable high jinx that all adolescents experience.

In the book, *As I See It: From a Blind Man's Perspective* Revised edition, Robert Branco discusses numerous issues pertaining to blindness. Topics include; legislation, discrimination, employment, myths about blindness, and adaptive technology. This second edition includes two dozen new essays on website accessibility, relationships, Beep Baseball, personal care issues, and much more.

For more information about the author, Robert T. Branco, his other publications, and to order these books, visit <http://www.dvorkin.com/robertbranco/>

Disability Images: *Images You Can Trust*

DisabilityImages.com offers real images of real people with disabilities. The company byline is "Images You Can Trust," as all imagery is available in high resolution, and fully released and cleaned of logo and trademark issues. All images are available for general publishing. We attempt to cover the positive lifestyle of people with various disabilities, such as Spinal Cord Injuries, Muscular Dystrophy, Down Syndrome, Multiple Sclerosis, and Spina Bifida, etc. The website covers many aspects of life, such as careers, family life, sports, education and medicine.

New imagery is always coming available.

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