***Disability Issues***

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**In this issue:**

Fun and Affordable Ways to Enjoy Summer

New ADA Regulations

The Advocacy Corner

Running in the Mobility Impaired Division of the Boston Marathon

Nine Time Boston Marathon Champion Inspires Area Groups

Information Briefs

**From the Editor:**

Dear Readers,

Summer is finally here! After our challenging weather this winter and spring, I am especially grateful for the simplicity of walking out my front door without having to deal with snow, ice and rain. To help you enjoy the great outdoors, we have a longer than usual article with many fun and affordable things you can do this summer. We hope this will stimulate ideas for you to try some new activities or re-engage in an old favorite.

You’ll also hear stories from two individuals with disabilities who have run the Boston Marathon. If you thought the only way to participate in the Marathon with a disability was in the wheelchair division, you are in for a wonderful surprise!

For those who remember reading Bill Henning’s article in the spring issue, Bill encouraged us to be loud, proud Disability Activists. In this spirit, we bring you the “Advocates Corner”, which shares a story that demonstrates how one person with a personal mission can be a powerful advocate and have big impact. Advocacy often starts small, local and personal. What is one thing you keep saying to yourself “How can this be? Why is this okay?” and what’s one action you can take toward advocating for change?

Marianne DiBlasi, Editor

**Fun and Affordable Ways to Enjoy Summer**

**By Sandy Alissa Novack**

Gas prices are up, and odds are your income is not up. We all need relief this summer − from the growing expenses in the economy, from the summer heat, from being pale after being inside this snowy winter, and maybe from not knowing what is both fun and affordable.

Nothing is more affordable than FREE. So, wherever you live, pull up a chair and read your local newspapers. For example, I like The Boston Phoenix, and they have a “Free Stuff” column each week. For April 16, 2011 they were listing a discussion at the Boston Public Library on Christopher McDougall’s Born to Run: A Hidden Tribe, Superathletes, and the Greatest Race the World Has Never Seen, a book about running but also about life. Of course, if I were a runner I would also have taken note in the Phoenix’s Fairs and Festivals column of the April 15 listing for the FREE John Hancock Sports and Fitness Expo at the Hynes Convention Center, geared toward runners of all levels and featuring exhibitors from across the country. Check out The Boston Phoenix for information about upcoming FREE events throughout the year.

**Zoos**

I grew up near the Forest Park Zoo in Western Massachusetts. I have fond memories of seeing peacocks strutting their stuff, feeding the ducks with my mother, my grandfather buying me a helium balloon from the vendor outside the entrance to the park, and standing in awe of the beautiful polar bear. I admit I wasn’t as fond of the Monkey House. Decades later, I still think zoos can feed anyone’s love of nature and animals. Now I live near the Franklin Park Zoo in Boston. For $75 a year, family membership to the Zoo provides admission for two named cardholders plus up to four children under 18 to both the Franklin Park Zoo and the not too far away Stone Zoo in Stoneham. It also provides a 10% discount to all gift shops and food concessions, and discounted admission to over 100 zoos nationwide. This past November, Belmont Medical Supply donated a Pride Victory 9 motorized scooter to Franklin Park Zoo, and another to Stone Zoo. Guests may rent these on a first-come, first-served basis; call the zoo for advance reservations. Guests who rely on service animals may bring the animals into the Zoo, provided the animals remain properly leashed. Consider visiting a zoo near you, often and lovingly.

**Everyone Outdoors**

If you visit [www.everyoneoutdoors.blogspot.com/](http://www.everyoneoutdoors.blogspot.com/) you will find a comprehensive community resource for people with disabilities who love the outdoors and who want to find out about everything from exploring new recreational opportunities to learning about adaptive equipment. Marcy Marchello is the site host and the coordinator for the Massachusetts Department of Conservation and Recreation’s (DCR) Universal Access Program. If you want to receive notices of seasonal updates to DCR’s offerings, you can enter your email address on their website or you can contact Marcy by email at [marcy.marchello@state.ma.us](mailto:marcy.marchello@state.ma.us) or phone at 413-545-5758 and ask her to put you on the mailing or email list.

As of the writing of this article, the blog has an exciting post about flying kites, which includes a mention of a man with epilepsy who flies one on America’s Got Talent. The blog also provides a link to Beach Wheelchair locations in MA and lists ten all-persons’ trails at the Massachusetts Audubon Sanctuaries, including Broad Meadow Brook in Worcester. Worcester residents enjoy FREE admission to Broad Meadow, and Mass Audubon members have FREE admission, too. Otherwise, current fees for Broad Meadow are $4.00 for adults and $3.00 for children or elders. The Nature Center, restrooms, and the Troiano Brookside Trail are universally accessible. See the Everyone Outdoors blog for a comprehensive listing of many more statewide accessible recreational options.

**Sailing**

Whether or not you like to eat spinach as much as Popeye, you too can become a sailor. There are multiple great locations in Boston where you can learn to sail. Piers Park Sailing Center in East Boston [www.piersparksailing.org](http://www.piersparksailing.org), phone 617-561-6677) is a very special adaptive sailing opportunity. It provides FREE, fully inclusive educational programs for underserved youth who are living with a disability. Membership by others helps support the FREE program for city youth, and the sailing center also offers a limited number of annual scholarships. The Adaptive Coordinator, Maureen McKinnon-Tucker, is a paraplegic who won a Gold Medal at the 2008 Paralympics Games. Other staff and volunteers may have hearing, sight impairments, ADHD or other challenges. Community Boating in Boston [www.community-boating.org](http://www.community-boating.org), phone 617-523-1038) offers a Universal Access Sailing Program with membership dues of $1 per season for kids and people with disabilities. They have a new dock, ramp, designated slip for adaptive sailboats, and both a wheelchair and Hoyer lift on site.

**Fourth of July**

What are you doing for 4th of July festivities? Check out [www.july4th.org](http://www.july4th.org) to learn about the Boston Pops and Fireworks Spectacular that takes place along the Charles River. The event is FREE. Handicap accessible restrooms can be found at all restroom locations. People with disabilities can be admitted on a first-come, first-served basis to the right of the Hatch Shell, within the Oval, to a designated handicapped section. If you prefer fewer crowds or want to support your own town’s plans, check your local community’s newspaper for a listing of events. Don’t forget to pack a picnic meal to celebrate Independence Day. Not only is it traditional, it’s also relatively low cost and fun for the whole family.

**Antiquing**

The Brimfield Antiques Show is the largest outdoor antiques show in the world, according to the website [www.brimfieldshow.com](http://www.brimfieldshow.com), with over 6,000 dealers and 130,000 visitors during the course of each week. The next two show dates are July 12-17 and September 6-11, 2011. Several of the fields charge admission fees but the majority of the fields are FREE. The antique show is in a field with loose to hard-packed gravel. Check the website for more details to determine if this venue is accessible for you and your family. About parking − the least expensive parking is not close to the dealers, so shuttles are provided. The most expensive parking is $10.00 per day along Route 20.

**Free Treats**

I remember helping my dad wash the family car when I was a child. Mostly I remember getting wet! Nowadays, ScrubaDub Auto Wash Centers ([www.scrubadub.com](http://www.scrubadub.com)) offer a FREE “Works Wash” to Car Care Club Members on their birthday. The car care club costs $6.95 for lifetime membership as long as you own your car. The Works Wash normally would cost $18.00 at my local ScrubaDub in Natick and Brookline and includes an exterior wash, under body wash, rust inhibitor, and wheel cleaning.

What is summer without ice cream? Friendly’s was founded in 1935 in Springfield. A double-dip cone at that time cost five cents. If you go to [www.friendlys.com](http://www.friendlys.com) and click on “Join BFF” you can join the Friendly’s club Best Friends of Friendly’s. You then get a FREE three-scoop sundae just for joining when you buy an adult entrée and for your birthday, offers will be emailed to you. Besides being partial to their strawberry ice cream, I like the fact that Cones for Kids is the chain’s annual Valentine’s Day period fundraiser. Since 1981, the funds raised from Cones for Kids support Easter Seals Camp Friendly’s programs, which give children and teenagers with disabilities the chance to attend Easter Seals summer camps. Head home with your ice cream and take care of that sunburn you got from being outdoors today. And remember, this article has only scratched the surface of what you can do when you go outdoors this summer, so be open to exploring some new fun and affordable things you might enjoy doing.

*Sandy Alissa Novack is on the Editorial Board of Disability Issues and is a consumer advisor on the Beth Israel Deaconess Medical Center’s Universal Access Advisory Council.*

**NEW ADA REGULATIONS**

Important changes to the ADA Title II and Title III regulations are in effect starting March 15. Title II applies to state and local governments. Title III applies to the private sector: stores, hotels, day care centers, non-profit organizations, medical providers, etc. Most of the changes in the two regulations are the same.

**What are the changes?**

**Service Animals**

The definition of service animals now only includes dogs. Other animals, whether wild or domestic, do not qualify as service animals. Dogs must be individually trained to do work or perform tasks. Dogs that are not trained to perform tasks that mitigate the effects of a disability, including dogs that are used purely for emotional support, are not service animals. The regulations also clarify that the animal must be under the handler’s control at all times, the handler is responsible for the animal’s care, and which questions can and cannot be asked in regards to requiring proof that the dog is a service animal.

**Miniature Horses**

Although not under the definition of service animals, the regulations permit the use of trained miniature horses as alternatives to dogs, where appropriate. Assessment factors to determine appropriateness include the type, size, and weight of the miniature horse; whether the facility can accommodate these features; whether the handler has sufficient control of the miniature horse; whether the miniature horse is housebroken; and whether the miniature horse's presence in a specific facility compromises legitimate safety requirements that are necessary for safe operation.

**Wheelchairs and Other Power-Driven Mobility Devices**

The regulations distinguish wheelchairs and other power-driven mobility devices (OPDMDs). OPDMDs are mobility devices not designed for people with disabilities, but which are often used by people with disabilities (such as the Segway). Wheelchairs must be permitted in all areas open to pedestrian use. OPMDs must be permitted unless their use would fundamentally alter programs, services, or activities; create a direct threat or create a safety hazard.

**Ticketing** (not parking tickets - tickets to sporting events, concerts, theater, etc.)

Tickets for accessible seating must be available to purchase during the same hours; during the same stages of ticket sales (pre-sales, promotions, lotteries, wait-lists, and general sales) and through the same methods of distribution (phone, in person, internet, third party) as tickets for non-accessible seating. The regulations also include requirements concerning information about the location and availability of accessible seating, hold and release of accessible seating to persons without disabilities, prevention of the fraudulent purchase of accessible seating, and the ability to purchase multiple tickets when buying accessible seating.

**Effective Communication**

The regulations include video remote interpreting (VRI) services as a type of auxiliary aid that may be used to provide effective communication. To ensure that VRI is effective, the regulations include performance standards for VRI and requires training for users of the technology. The regulations state that a minor child may not be used to interpret or facilitate communication except under emergency situations.

More ADA Title II and Title III regulations changes go into effect next year on March 15, 2012. We will discuss those changes when they become available.

Please contact the New England ADA Center if you have any questions. Email adainfo@newenglandada.org or call 800-949-4232 voice/tty (New England only).

**THE ADVOCACY CORNER**

**In Her Own Words: Advocacy at the Local Level –**

**Massachusetts Mom Advocates for $2M to Upgrade Neighborhood Train Station**

When Jean Batty and her husband relocated their three children to Winchester, Mass., in 2007, they chose a beautiful home in part because of the ease of public transportation and the excellent local school system. Nestled about 20 minutes outside of Boston, Winchester offered just want they wanted with one unknown exception—their nearby commuter rail stations did not offer accessibility for their then 2 ½ -year-old son, Theo, who has Spina Bifida and uses a wheelchair. The stay-at-home mom, and then future Chair of the local Disability Access Commission, decided to take action for change at the Wedgemere Train Station by working with local, state, and national leaders to make the platform accessible.

Jean reflects on her efforts to bring accessible transportation to her neighborhood.

**What was it about this issue that fueled your efforts to have your local rail station made accessible?**

Fundamentally, I wanted my son to have access to all the educational and employment opportunities that Boston has to offer. But it was more than that. Here we are, celebrating the 20th anniversary of the Americans with Disabilities Act (ADA), and many rail stations across the country are still completely inaccessible. I was shocked when I discovered this loophole in ADA, and I kept thinking, “How can this be? Why is this okay?” The “key stations” which are accessible are generally located in more expensive neighborhoods—not ones in which people with disabilities can usually afford to live.

**What was the cost of your advocacy to your family?**

Of course the time I invested in this project was part of the cost, but more significant was the loss of privacy. Our family needed to share our story, to share our hopes and dreams for our son, and to put ourselves in the public eye. But the payoff has been much greater than the cost. In addition to accessibility for our son, we have made it possible for others with disabilities to make the commute to Boston. Someday, as we age, my husband and I may even benefit. Others invested of themselves to pass ADA 20 years ago, but I see this as a relay race. Our family has made a small contribution to the solution—it has a ripple effect.

**What was your most powerful tool in effecting this change?**

I founded and chair the Disability Access Commission for our community, but my position on that board was not my most effective tool. It was the power of a mom speaking for her child. I was not just the head of yet another commission at a hearing—I was the mother of a child who was unable to travel to Fenway to see a Red Sox game. We sent Theo's video to government officials and used it to encourage people to write to their Representatives. Stories move people more effectively than facts or statistics.

*Article reprinted with permission from Insights into Spina Bifida magazine - Volume 4, Number 1, Winter 2011.*

**Running in the Mobility Impaired Division**

**of the Boston Marathon**

**By Tanya Skypeck**

The Boston Marathon is widely considered the most elite foot race in the world, but in April 2006 I somehow found myself in the first corral, in the first wave of runners, just after the professional competitors, a mere few feet from the start line, surrounded by lean, fit, wiry men wearing the jerseys of their countries, proud to represent their nations in such an event. I, a young woman with under-formed feet and a t-shirt with the nickname, “Spike,” scrawled across the back in permanent marker, felt woefully out of place. But moments later when we began running, I knew I could finish what I’d started, regardless of a mobility impairment, and I was most grateful to have my chance to run this storied marathon.

Since the mid 1980’s, the Boston Athletic Association (B.A.A.) has made its signature event, the annual Boston Marathon, as accessible to people with disabilities as a marathon could possibly be. In addition to the Push Rim Wheelchair Division, which also enjoys considerable international notoriety, the B.A.A. Boston Marathon has the much lesser known categories of a Visually Impaired/Blind Division and a Mobility Impaired Division.

Would-be runners must qualify for entry into the Boston Marathon based on finishing time from a previous, certified marathon. Required qualifying times vary by age and gender, and are set by the B.A.A. based upon a careful calculation of the expectations for superior physical fitness in certain population segments. But the B.A.A. also recognizes that there are perhaps additional considerations and obstacles for runners with certain physical disabilities to factor in when determining performance excellence. So runners with verified mobility impairments qualify under their own category. Regarding Boston Marathon qualification, the B.A.A. website states, “Individuals with permanent disabilities that affect ambulation and who would not otherwise qualify for entry in other divisions are being granted the following extended qualifying times: The qualifying time is 6:00 hours for individuals who, because of the nature of their disability, have difficulty ambulating. The qualifying time is 8:00 hours for individuals who, because of the nature of their disability, need mobility aids such as prosthetics, leg braces or crutches to ambulate.”

For those requesting to be considered under the mobility impaired category, verification of a qualifying disability is relatively easy. A representative from the B.A.A. was personally in touch with me to send a single, simple form that needed a signature from a medical professional, to answer my questions about where to go and when on race day, and to follow up after the race regarding my marathon experience.

For many marathoners, qualifying for the Boston Marathon is a life-long goal, and to be able to officially run it is a great privilege. Because of the consideration that the Boston Athletic Association gives to long-distance runners with disabilities – but with dreams as lofty as any other runner – I can proudly say, “I qualified.”

*Tanya Skypeck is a research coordinator in the Center for Health Policy and Research at the University of Massachusetts Medical School and a member of the Disability Issues editorial board.  She has run four marathons and is currently in training for a 10k, which will hopefully prepare the way for more marathons.*

**Nine Time Boston Marathon Champion Inspires Area Groups**

**By Tim Sullivan**

Ernst van Dyk, wheelchair racing legend made several area appearances prior to racing in the 115th Boston Marathon. Ernst shared his inspiring message of overcoming adversity, stressing to the crowds throughout the day that true victory can mean many things and is often borne from how you get back up when you get knocked down. Ernst finished third in a photo finish at the Boston Marathon. However, with his 9 titles, he holds the record for most wins for anyone in any division in the storied race’s 115 year history.

 “Sports have given me the opportunity to help others in realizing that life does not end with disability but that it’s merely a beginning to a new way of life,” said Ernst Van Dyk. “My hope is that through my story people are inspired to try new challenges and enjoy their lives in ways they thought might never be possible.”

Ernst was born in apartheid South Africa with congenital limb differences. Doctors told his parents he would only face a lifetime of hardship. Rather than listen to what people told him he could not do, Ernst was raised to believe that anything was possible. Today, Ernst is a world-renowned athlete, advocate, and champion who is an inspiration to thousands across the globe.

On behalf of Spaulding Rehabilitation Network and in partnership with Massachusetts Rehab Commission (MRC), a few days before the Marathon, Ernst addressed a crowd of hundreds at the Riverview School for youth with complex language, learning and cognitive disabilities in Sandwich. He also visited with patients and staff at Spaulding Hospital Cape Cod and ended his day by being honored by MRC at the Massachusetts State House addressing legislators, youth groups and community organizations. Beginning in 2003, the Spaulding Rehabilitation Network has been one of van Dyk’s major sponsors.

“To be able to bring to our community such a decorated athlete and remarkable person like Ernst who is such a symbol of perseverance is something MRC is very proud of. I know our constituents and the many attendees found his message both uplifting and inspiring,” said Commissioner Charles Carr, Mass Rehab Commission.

“Spaulding is so proud to have this longstanding sponsorship with Ernst to support him as he continually rewrites the record books and challenges perceptions of what is possible,” said David Storto, President, Spaulding Rehabilitation Network. “Ernst embodies the very best qualities of strength and dedication that our caregivers and courageous patients display each day at Spaulding.”

In addition to marathon victories all over the world, Ernst has won multiple medals at the Paralympics, including gold at the 2008 games in Beijing. Ernst was also honored in 2006 as the Sports Star of the Year by the International Laureus Sport Foundation, joining figures such as Lance Armstrong, Serena Williams and Roger Federer.

Ernst is now looking ahead to how he can continue to expand his impact for the community with disabilities worldwide. He launched a new sports equipment brand, Enabled Sport, based in Africa that offers a range of sports and recreational products for persons with a disability. In just two years, Enabled Sport is already one of the largest equipment dealers in Africa.  Beyond the business ventures and racing victories, it was obvious throughout the day that his greatest impact is the example he gives to all who meet him that anything truly is possible if you believe in yourself.

*Tim Sullivan is Director of Communications, Partners Continuing Care & The Spaulding Rehabilitation Network.*

**INFORMATION BRIEFS**

**Physical Access Requirements Briefing Held by MHA**

On May 10, 2011, the Massachusetts Hospital Association (MHA) held a briefing for its hospital members covering the physical access requirements for patients under the federal Americans with Disabilities Act (ADA). The program provided hospitals with general information about addressing physical barriers to accessing care and included specific examples from hospitals, clinicians, and patients as to what can be done to change the culture, design of the buildings, and diagnostic equipment. John Auerbach, Commissioner of the Massachusetts Department of Public Health, opened the day with remarks about the need to improve access to health care for people with disabilities and the important role that hospitals play in that effort. Speakers included Boston Center for Independent Living (BCIL) board members Lisa Iezzoni, Professor of Medicine at Harvard Medical School, and Pam Daly, who spoke about the impact of problems with access on people with disabilities at the systemic and personal levels. Minh Vu, Partner and Team Leader of the ADA Title III Practice Group of the law firm Seyfarth Shaw provided an overview of the ADA’s requirements regarding hospitals. Janet Razulis, Project Manager for the Disability Access Initiative at the Brigham and Women’s Hospital and Zary Amirhosseini, Program Manager at the Massachusetts General Hospital described their own internal efforts to evaluate the accessibility of their facilities and processes and implement necessary upgrades. UMass Memorial Medical Center’s (UMMC) efforts to accommodate individuals with disabilities in Central Massachusetts were described by Gary Valcourt, Senior Director, Office of Capital Planning and Scott Reynolds, Director, Facilities Project Management at UMMC. Contact BCIL at 617-338-6665 if you have hospital access concerns.

**USBLN® and ODEP Partner to Promote Employment of Qualified Job Seekers with Disabilities**

WASHINGTON, DC (March 14, 2011) - The US Business Leadership Network (USBLN®), together with the U.S. Department of Labor's Office of Disability Employment Policy (ODEP), today announced a partnership aimed at further promotion of the recruitment and hiring of qualified individuals with disabilities. The Workforce Recruitment Program (WRP) database contains more than 2,200 pre-screened college and university students with disabilities who are looking for summer or full time jobs. [www.wrp.gov](http://www.wrp.gov).

**Save the Date!**

Get ready! On September 23, 2011 a statewide initiative called ‘Products and Technologies that Change People’s Lives – Universal Design and Assistive Technology in Massachusetts’ will take place at the Hynes Convention Center in Boston, MA.

This initiative, which consists of a conference, expo, design competition and summit, was born from the vision of the Massachusetts Executive Office of Health and Human Services (EOHHS) to elevate assistive and inclusive technologies to a whole new level of significance in the Commonwealth. The Institute for Human Centered Design is the convener of the events of the day which will showcase state-of-the-art and evolving technologies and products for people with disabilities and older people, for consumers, employers, educators, and others to demonstrate how emerging and cutting edge technology can improve the ability to work, live, learn and play across the spectrum of ability and age.

The conference website will launch soon with more information on how to register, participate in the design competition and become an exhibitor. To get added to the mailing list for general information send an email to: [info@changepeopleslives.org](mailto:info@changepeopleslives.org) or visit the website at [www.changepeopleslives.org](http://www.changepeopleslives.org).

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