

PossAbilities & you

Summer 2008
www.possabilities.com

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A Special Little Girl

Abbey Umali is the Muscular Dystrophy Association's National Ambassador for 2008. Her responsibilities as ambassador will take her throughout the U.S. to raise awareness of muscular dystrophy. See page 2 to learn more about this special little girl.

PossAbilities



LOMA LINDA UNIVERSITY
MEDICAL CENTER EAST CAMPUS

Abbey: Small Girl *with a Big Message*



My name is Abbey, I'm 9 years old, and I live in Redlands, Calif., with my mom and dad.

I attend Montessori School in Redlands, and I love school. Most of all, I like reading, math, and geography (and recess, of course). One of my favorite things is learning state capitals.

After school, I stay very busy reading, singing, swimming, riding my bike, and spending time with my friends. I also play the piano, love to act, and I like to play lots of games. I have pet bunnies (someday I hope to have a kitty or a hamster), and I have lots of stuffed animals like Lily, Aggie, Bluey, and Pandia.

My family is really fun. We like to make each other laugh a lot. My mom,

“The message I want to tell people is to please help kids with muscular dystrophy. Even if everyone gives a little, it'll add up to something big,” says Abbey, pictured above with her parents.

Wendi, is a physical therapist (she's a big help with my exercises) and my dad, Joel, is a dentist. He cleans my teeth and plays the piano with me. I love to cuddle with my family, travel to different places with them, and play games together, especially Monopoly and Blink.

For the past two years, I've really liked being the Muscular Dystrophy Association's (MDA) Goodwill Ambassador for California. I have traveled across our big state to tell people about all the wonderful things

MDA does. MDA is going to find cures for muscular dystrophy. Being in front of lots of people has been a good experience for me because, as national goodwill ambassador, I'll be visiting lots of cities and telling people about MDA.

I hope I'll be able to visit with you sometime this year. The message I want to tell people is to please help kids with muscular dystrophy. Even if everyone gives a little, it'll add up to something BIG. And that will do a lot of good for a lot of people. ●



Physical Therapy Helps Make Me Stronger

I have a form of Charcot-Marie-Tooth disease. It affects my nerves and muscles. I don't make enough myelin, which means that my muscles don't hear the message from my nerves loud enough. My muscles are weak so I use braces to help me walk. I also have trouble balancing so I fall down a lot. I work really hard in physical therapy to make my muscles stronger and my balance better.



KEEP KIDS MOVING! Special exercises for children with muscular dystrophy

If your child has muscular dystrophy, she or he is at risk for a complication known as contractures. This happens when muscles waste away and joints freeze in place.

Range-of-motion exercises help prevent contractures. Have your child perform the motions, if possible. Passive exercise, when you or a physical therapist moves your child's body for him or her, is another option.

Your child should do each of these moves three to five times. Hold each position for 10 to 30 seconds.

■ **Hip and knee.** Lying down, bend the knee and move it toward the chest. Then return the leg to its original straight position. Repeat with the other leg. If your child needs help, place your hands on his or her knee and ankle and perform the movement.

■ **Finger.** Hold the hand up with fingers touching each other. Then spread the fingers apart. Return to starting position.

■ **Wrist.** Bend the wrist forward, straighten, and then bend backward. Support your child's arm and hand as she or he performs the exercise.

Keep an Eye Out for the 2009 PossAbilities 7th Annual Triathlon

We had over 1,000 racers in attendance this year. It was the best turn out yet! Thank you to all of the volunteers that helped make this such a successful gathering! Get ready to mark your calendar for next year's triathlon. It will be bigger and better than ever! Look for the date in a future issue of *PossAbilities & You*. (Date has yet to be determined.)

Cover. XXX. **2.** Go Abbey! She is first out of the gate in the bike portion of the kids triathlon. **3.** Our photographer, Terry Martin, is Abbey's closest competition! **4.** Willie Stewart, Abbey Umali, and Julie Swale-Ertel, National team member and representative of the U.S. at the Beijing Olympics are joining together as first class athletes at the PossAbilities triathlon.



The *Team Approach* to Raising Children with Disabilities



For children with disabilities, life is not an individual sport. Kids do best with a team to support them. Key members include parents, doctors, and teachers. Here's how to help your child make a game plan for a healthy, full life:

- **Do your homework.** Learn about your child's disability. Find out what causes the condition and how to manage it. Talk with other children and parents who share the same challenges.

- **Set goals and plans.** Write down your child's current medical and educational needs. Also write out what she or he would like to do when older. Share the information with everyone on the team. This will ensure your child gets proper assistance every day as well as help him or her reach long-term goals.

- **Promote healthy behaviors.** The same rules that keep all kids healthy apply to children with disabilities. This

includes eating plenty of fruits and veggies, getting regular exercise, and sleeping enough.

- **Get help.** Extra resources may be available for your family. For example, your child could get disability payments from Social Security. Special education and job training programs can support him or her. Ask your child's doctor or seek legal counsel for more information.

- **Balance care and independence.** Tell your child to ask for help when he or she needs it. Also encourage independence. For example, your child may be able to track doctors' appointments on a calendar. Older children can run errands or meet with doctors alone.

- **Take care of yourself.** Keep your own mind and body healthy. Join a support group, tell your family how you feel, and ask for assistance. ●

PROTECT YOUR SKIN FROM THE SUN

- Pick a broad-spectrum sunscreen with an SPF of 15 or higher that blocks both UVA and UVB rays.
- Apply at least an ounce of sunscreen 30 minutes before you go out. Reapply it every couple of hours—or more often when you sweat or swim.
- Avoid unneeded sun exposure. Sit under an umbrella or seek shade from 10 a.m. to 4 p.m.
- Dress in protective clothing. Wear lightweight, light-colored garb. Choose a hat with a wide brim.
- Stay out of the sun if you're taking medications that make you more prone to sunburn. Ask your doctor or pharmacist.
- Wear sunglasses that shield your eyes from 99 percent of UVA and UVB rays.
- Avoid tanning beds. They're not safe alternatives to the sun.

FREE Lip Balm

Call 1-877-LLUMC-4U for your FREE lip balm sponsored by PossAbilities. Quantities are limited.



The World Awaits!

Vacation Locations to Fit Your Style



On vacation, you shouldn't have a care in the world. Whether you want to raft the Grand Canyon or just lounge on a beach, choosing the right destination and resort will make for smooth sailing on your summer vacation.

■ **For the active traveler:** Many travel companies advertise their active wheelchair-accessible adventures on the Internet. You can sail the Mediterranean or ride horses in Arizona. Colorado Discover Ability offers river trips, waterskiing, and cycling tours: www.cdaioa.com. Craving the powder? Hit the slopes with the Utah-based National Ability Center. Rent special equipment or take a lesson from an instructor trained in adaptive skiing: www.discovernac.org.

■ **For the nature lover:** Famous national parks such as Yosemite and Yellowstone have wheelchair-accessible scenic trails, lakeshores, and recreation

areas. And nearly all state parks have some accessible trails. Visit the National Multiple Sclerosis Society's Web site at www.nationalmssociety.org for a sampling of some of the country's best wheelchair-accessible nature trails. Find information on specific parks at www.nps.gov.

■ **For the cruise fan:** Cruises operated by U.S. companies have to meet U.S. disability standards. But other carriers can vary widely in level of accessibility. Search the Cruise Lines International Association's Web site, www.cruising.org, to find cruise lines that offer the features you need.

■ **For the beach bum:** Niche resorts all around the world, from Mexico to Greece to Thailand, specifically cater to people with disabilities. If you're booking through a hotel chain, talk with someone at the specific location you'll be visiting before you go to make sure it meets your needs. ●

Where to Stay

■ **Call your resort directly.** The central reservation system usually won't have all the information you need to know to make sure your room is accessible. Talk with the local hotel you'll be visiting. Ask for someone who can tell you about the rooms for people with disabilities. Make sure you're talking with someone who has actually been in the room. Should you have trouble getting the information you need, speak with the general manager.

■ **Write it down.** Ask the hotel to document your needs. Write down the name of the person you talked with. That way you can show you're entitled to your requests if there's a problem.

Resorts/Hotels that Cater to People with Disabilities

■ **Microtel Inns and Suites**

Meets all ADA-compliance guidelines in designated rooms at their more than 300 U.S. and international locations.

1-800-771-7171

www.microtelinn.com

■ **Walt Disney World Resorts**

Offers special accommodations at their resorts, attractions, and restaurants for guests with disabilities.

Special reservations: 407-939-7807;

TTY line: 407-939-7670

www.disney.go.com

■ **Stagecoach Trails**

This Arizona dude ranch provides disabled travelers and their families opportunities to enjoy horseback riding and an accessible swimming pool.

520-854-1869

www.stagecoachtrailsranch.com

■ **Freedom Shores**

This intimate, full-service beach resort features nine rooms that are completely wheelchair accessible and 30 fully equipped recreational vehicle sites located on Mexico's Yucatan Peninsula.

951-801-2716

www.isla-aguada.com



GROUNDBREAKING CELEBRATION

On February 25, more than 300 guests gathered for the groundbreaking celebration of the Tom & Vi Zapara Rehabilitation Pavilion. Among attendees were PossAbilities members, patients, and employees of the Loma Linda University Medical Center.

In lieu of ribbon-cutting or earth turning, patients joined up with staff to plant dwarf citrus trees that will be placed within the pavilion once it is completed.

During her message, Dr. Lyn Behrens, the soon-to-retire president and chief executive officer of Loma Linda University Adventist Health Sciences Center, said of the project, "We are committed to transforming lives, particularly those whose lives have had these kinds of difficult events and challenges."

Construction for the new pavilion is under way and scheduled to finish in late 2009. For further information regarding rehabilitation services at Loma Linda University Medical Center East Campus, please call **1-877-LLUMC-4U**.



Rehabilitation Pavilion Provides a *Healing Environment*

The Tom & Vi Zapara Rehabilitation Pavilion's design focuses on environment and its impact on well-being.



The new Tom & Vi Zapara Rehabilitation Pavilion will be unique to the Inland Empire—combining whole person care in an innovative therapy setting. It will be a 24-bed, 30,000-square-foot rehabilitation facility at East Campus dedicated to treating patients who have suffered from a recent disability.

The facility's evidence-based design focuses on environment and its impact on a patient's well-being. Studies show that healing environment models can reduce a patient's anxiety, blood pressure, use of pain medication, and length of stay.

All patient rooms will be acuity-adaptable, private, and sizeable enough for loved ones to room-in. The building will provide access to nature through adjacent outdoor patios, abundant natural lighting, and mountain views. In an effort to eliminate environmental stressors that inhibit a patient's restful recovery, the building will have sound absorbing ceiling tiles and flooring, as well as room comfort controls within the patient's reach. Special educational areas will be

dedicated for assisting patients in making informed decisions regarding their condition and treatment options.

The ground floor will be called "Independence Square," where patients and therapists explore everyday tasks such as maneuvering around chairs, climbing stairs, and counting change. Independence Square will likely include models of a grocery store, boutique, bank, bedroom, kitchen, and a car.

Unlike traditional hospital design, the pavilion's features encourage families to remain engaged during the patient's recovery. Positive distractions for patients and their families will play a strong role in recovery. Various programs, such as horticulture and pet therapy, as well as family zones with lounges, kitchenettes, and Internet access will be built in.

"We designed the Pavilion with our patients' best interest in mind. When our families and patients connect through nature, they heal faster and better," said Michael Jackson, senior vice president and administrator for Loma Linda University Medical Center East Campus. ●

Resource Guide

To find out more about **PossAbilities**, contact our office at **909-558-6384** or visit us on the Web at **www.possabilities.com**.



Join a Winning Team—Team PossAbilities!

Reap the benefits of a healthy lifestyle through Team PossAbilities. The team offers peer support, training, and more. Visit **www.teampossabilities.com** or call **909-558-6384** to join.

AMPUTEES

Amputee Coalition of America (ACA)

1-888-267-5669;
TTY: 1-865-525-4512
www.amputee-coalition.org

ARTHRITIS

Arthritis Foundation

951-320-1540 or
1-800-954-2873
www.arthritis.org

Juvenile Rheumatoid Arthritis (JRA)

951-320-1540 or
1-800-954-2873
www.arthritis.org

BLINDNESS

Blindness Support Services

951-341-9244
Information, referral, housing support, counseling, Braille tape transcription, speakers' bureau, transportation assistance, and prevocational training.
www.blindnesssupport.com

Braille Institute

714-821-5000
www.brailleinstitute.org

National Federation of the Blind

410-659-9314
Resources include publications, aids and appliances, conventions, employment, and training.
www.nfb.org

American Foundation for the Blind

1-800-232-5463
Addresses critical issues facing people with visual disabilities including employment, independent living, literacy, and technology.
www.afb.org

BRAIN INJURY

Brain Injury Association of America

1-800-444-6443
Creating a better future through brain injury prevention, research, education, and advocacy.
www.biausa.org

National Brain Injury Information Center

1-800-444-NHIF (6443)
www.biausa.org

MUSCULAR DYSTROPHY

Muscular Dystrophy Association

951-369-0720
www.mda.org

MULTIPLE SCLEROSIS

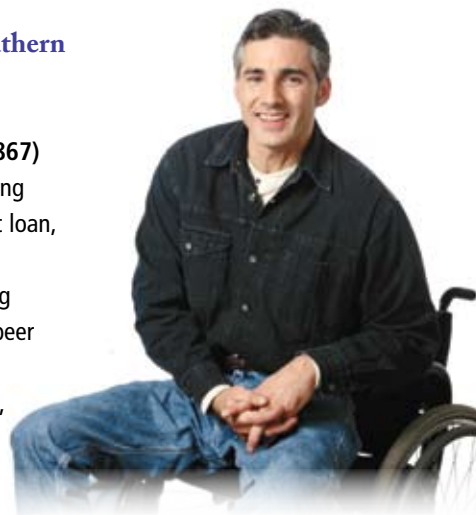
National Multiple Sclerosis Society/Southern California Chapter

310-479-4436 or
1-800-FIGHT-MS (344-4867)
Provides resources regarding clinical centers, equipment loan, therapies, aquatics, social services, education, lending library, speakers' bureau, peer counseling, respite care, advocacy, self-help groups, and employment services.

SPINAL CORD INJURY (SCI)

California Paralyzed Veterans Association

562-826-5713 or
1-800-497-0565
Provides resources for veterans.
www.CALPVA.org



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1-800-440-IEHP (4347) Phone
1-800-718-IEHP (4347) TTY

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Inland Empire Disability Resources **expo**

Save The Date

Thursday, October 23, 2008 9 am - 2 pm

Exhibits & Workshops on:

Health ■ Housing ■ Transportation ■ Advocacy
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cost: FREE

where: Loma Linda University Medical Center
25040 Stewart Street, Loma Linda, CA 92354

info: (909) 890-5833 (909) 890-1623 TTY
IEDisabilitiesCollaborative@gmail.com

Please request reasonable accommodations
and alternate formats at least 2 weeks prior

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All Aspects of Life

The IEDC is sponsored by Inland Empire Health Plan and
PossAbilities of Loma Linda University Medical Center
East Campus



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WILLIE'S CORNER



Willie's Corner is about participation, training tips, and just being involved in all aspects in life.

This year's Redlands Bicycle Classic Hand

Cycle Division Race had it all— integration and inspiration. World record holder and Ironman world champion Carlos Moleda (a former Navy SEAL) flew in from South Carolina to participate. Then there was Dan Davies, a retired San Bernardino City police officer, who was recovering from a recent accident and trained hard over the last four months to make his racing debut. Malik Mohammed, who lost his legs in Afghanistan when he stepped on land mines, finished the race after only riding a hand cycle twice. Jimmy Grissom, encouraged by Carlos Moleda, was able to complete three laps for the first time during the hand cycle clinic and rode to the best of his ability when many told him he wouldn't be able to do it. Thanks to everyone who participated and volunteered for this inspirational event.

Willie "One-Arm Willie" Stewart is a four-time Ironman finisher, Paralympics silver medalist, kayaker, and Olympic torchbearer.

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