

REVOLUTIONS

NEWSLETTER FOR CENTER FOR INDEPENDENT LIVING SOUTHWEST KANSAS

REFLECTIONS ON THE SEASON

Stacy Ritt

 Volume 3, Issue 2 December, 2006
INSIDE THE ISSUE
HOME SWEET HOME p. 2
SOMETIMES... p. 3
NEWS/ANNOUNCEMENTS p. 4
NEWS/ANNOUNCEMENTS p. 5
NEWS/ANNOUNCEMENTS p. 6

Welcome to this year's holiday edition of Revolutions. As the year comes to a close I find myself reflecting on all the changes that have occurred here at CILSWKS in this past year. We have grown and taken on new programs and staff, as well as additional management positions to address the continued needs of the ever changing diversity of the disability community. Please welcome the new Office Coordinators in Dodge City, Liberal and Garden City, as well the Program Coordinator. With this growth, there are the ever natural growing pains. We ask for your patience as we train the new staff to provide you with increased quality of services. We continue to be committed to the needs of you, our customer. We have added services to support individuals with developmental disabilities and will continue to improve the access to these services in the next year in our effort to provide choice and opportunities to all people with disabilities. CILSWKS has also partnered with Vocational Rehabilitation to offer placement and employment support, in addition to accepting Tickets to Work. In the past year we have worked to make ourselves more visible in outlying communities through the participation in community activities, and we will continue to do so. If you would like to learn more or would like to give a presentation to your group or organization contact the office coordinator at your nearest office. We have in development an accessible housing list for Southwest Kansas to assist the community in finding affordable accessible housing and working with landlords to identify area of improvement. We invite anyone interested in being involved or wanting more information on any of the programs mentioned or for any other questions to stop by your nearest CILSWKS office. As I close this edition I reflect back on the individuals who have been part of the CILSWKS family this past year and thank them for their spirit and contribution to empowering others to reach their dreams. To you, our consumers, thank you for sharing your lives with us and allowing us the opportunity to learn from you. We hope to continue to be part of your lives. Wishing you the best this holiday season and the year ahead, Center for Independent Living Southwest Kansas staff.



To Advocate for the Choices, Independence,
and Civil Rights of People with Disabilities

CILSWKS

Attn: Revolutions
111 Grant Ave
Garden City, KS 67846

Phone/TTY: 620 276-1900

Fax: 620-271-0200

1-800-736-9443

E-mail: revolutions@cilswks.org

www.cilswks.org

Nonprofit
Postage Paid
Garden City, KS
Permit No. 104
CILSWKS

HOME

SWEET HOME

Alejandro Barrigan had gone through what seemed another regular day at work. It was about time to head out for the day. He and a coworker were gathering trash around the corral; this was nothing new to them. His coworker approached him on the tractor so he could get on, but the unexpected happened. He was accidentally hit by the tractor causing him to fall over. It happened so quick that the tractor was unable to come to a complete stop before the tractor tire rolled over him. Alejandro was quickly flown to Wichita where they found his cranium had been cracked.

In Wichita, the family was told that Barrigan was going to die, but they refused to let him go without a fight. Alejandro's dad, Ramon Barrigan said, "If god is going to take my son away, I leave him in his hands, but I will not let him go without trying." He went ahead and signed the papers for surgery. Barrigan seemed to be ok, but after 24 hours the anesthetic had worn off and he was still not responding. The doctor told the family that Barrigan was living only with the help of the machines, which the family refused to remove. "If god is going to take him, he's going to have to do it with the machines still on him, and here he is now," said Minerva Barrigan, Barrigan's mom.

Barrigan was moved to Dodge City's Good Samaritan Center. Barrigan's mom was very happy with the care they were giving him there. She said there were two particular CNA's that not only fulfilled their duties with Barrigan because they had to, but because they wanted to. They became really attached to Barrigan, every time they checked on him they would give him an extra therapy out of their own will. To his mom, it was very evident that they really cared for him. She mentioned that one of the CNA's still comes and visits Barrigan all the way from Dodge City and he even decorated his room here in Garden City's Terrace Garden.

Barrigan's mom knew that the care he got in Dodge was very good, but she was only able to visit him once a week on Sundays. Transportation kept her from visiting more often and she wanted him moved to Garden City. She felt that she needed him here so she could visit more often and be able to speak to him more. "When I would only go to Dodge on Sundays, I would speak and speak to him, and he would not respond, he would just sleep." She wanted him closer to talk to him more; she is certain that it helps give him a faster recovery.

Barrigan was finally transferred to Garden City's Terrace Garden and she is now able to visit almost everyday. When he was transferred from Dodge City, he was already able to move his feet and body on his own with the help of a chair they provided in Dodge City. The chair allowed his feet to hang; his mom believes it is what helped him gain movement. Terrace Garden did not provide this type of chair; instead he got one that didn't allow his feet to hang. She asked for that particular chair and they ordered it, but it took more than a year to get it. He lost some of his movements because of this, but now that he has the chair he gained them back. He is now able to stretch out his arms and legs on his own.

Mrs. Barrigan is still having problems with transportation and for this reason she would like to move Barrigan into her own home. With the school year starting up again, she has to baby sit her grandkids and is unable to be with Barrigan as much as she hoped. He has shown a lot of improvement from the time he was transferred from Dodge City. His mom believes that this is due to the fact that she is with him more and speaks to him. Sometimes she is not able to come in due to doctor visits or health issues of her own. There are times she doesn't go in for a whole week and she tries to explain to Barrigan why she couldn't.

"I tell him, Alejandro I couldn't come because I had a cold. Then he makes a face like if he was sad or upset, showing sentiment. I think that he understands me," she said.

She would also like him home because the care he is given at Terrace Garden is not as good as the care in Dodge City. When she doesn't come in as often she finds him in unsatisfactory conditions. She'll find him in uncomfortable positions or finds that he has not been given his scheduled showers. She doesn't think they care for him like they did in Dodge. There was an instance where she told them that he needed a rail on the bed like he had in Dodge City, that is was something good for him. They didn't listen to her request and the next day she came in they had bad news for her. They said he had fallen off the bed. "I had told you that the bed in Dodge had a rail," she told them. They finally got the rail for him after he fell off the bed. She has spoken with management about these issues and they fix them for a few days, but after a while it goes back to the same thing.

We asked Mrs. Barrigan what she thinks the care for his son would be like if she didn't come in to the nursing home at all. "I don't think he would be taken care of good," she responded. She thinks this way because she had noticed the type of care patients without families at Terrace Garden receive. "They can speak and they ask for help and the staff just walks by and they act like they don't hear them. I imagine it being like that with my son if I weren't here," she said.

"I want him home; I want him close to me. I know it's hard for me but I'm willing to do whatever I can, so he'll be close to me," she said. "I ask him if he wants to go home and he responds by moving his eyes a lot or closing his eyes. This he was not doing in Dodge," she added. She believes that as soon as he is able to react, react to where he knows what he's doing that he will be able to be completely independent again. For this reason she wants him home. So that she can be with him everyday and help him gain a faster recovery.



SOMETIMES

THOSE WHO SEEM TO BE DIFFERENT ARE NOT SO DIFFERENT AT ALL

COURTESY OF JESSICA CRAWFORD OF THE SOUTHWEST DAILY TIMES

Karalee Hill is a daughter, a sister, a friend to many and loving caregiver to her dog, “Little Bit.” She is kind, compassionate and genuine. When people meet her for the first time, those are the qualities and attributes society should see in such an amazing woman.

Hill was born with Sturge-Weber syndrome. One side of her body is just barely larger than the other, and one side of her brain is a bit larger as well. She has a large birthmark, known as a “port wine stain” on the left side of her face and an artificial eye. She has also experienced seizures since she was very young.

Unfortunately, many individuals who cross Hill’s path first notice her disability. Without taking the time to get to know her, she has been dismissed by many as handicapped, especially in her efforts to join the work force. “Many people in our community judge me and others like me by the way we look on the outside and never want to give us a chance,” Hill said. “Just because we have some handicaps doesn’t mean we are any different than anyone else.”

As one walks into her well-kept apartment she has called home for nearly eight years, one can immediately tell she is not afraid to dig in and work. She cares for her dog as if she were her very own child. Hill also walks approximately two miles per day. “I love to walk,” she said with a smile. “I walk about two miles everyday. Little Bit likes to go too. It is so good for us. It just feels good.”

Hill is clearly a hard worker. She takes care of herself and the things that have been placed in her care. Why, then, has she had such a difficult time finding a job? She believes discrimination may very well be the answer to that question. “I have experienced discrimination when it comes to applying for a job,” she said with genuine concern. “I would like to be given a chance in life to show who I really am.” As a self-described “dog nut,” she is quite the animal lover. She would love to work with animals in some capacity. She also expressed an interest in horticulture. “I would love to work with animals, I really enjoy being around them,” she said. “I also love flowers. I would love to work with flowers in some way.”

Hill has done her fair share of “pounding the pavement” in search of employment. However, she has been very discouraged by the results of her efforts. She has been stared at and talked down to repeatedly because she looks a little bit different on the outside.

But when she walks through her front door, Karalee Hill’s world changes. Her four-pound Yorkie, Little Bit, waits eagerly for attention and playtime. Little Bit doesn’t see Hill’s disabilities, she sees Hill as the rest of the world should. She sees her as a loving protector. Little Bit loves her unconditionally just because Karalee is Karalee. Little Bit knows Karalee is there to feed, walk and play with her because she is always faithful to care for her.

Karalee and Little Bit have a special bond that goes even a bit further than the special relationship between a pet and an owner. Little Bit is a service dog that has been specially trained to detect when Karalee is about to have a seizure. “Since she is certified, I can take her to the grocery store or even the hospital,” Karalee explained. “Because she is working.” The relationship between the two is very special. They enjoy spending time together, just playing or walking. “She never judges me,” Karalee said. “I really wish people could be more like that. I may look a little different, but I’m not. I am a regular person just like anyone else.”

Karalee is not asking for special treatment. She is only asking for a chance. A chance at a life that she, as an American woman, is entitled to. Before people decide to pass judgment on her and people like her, Karalee suggests reading Matthew 7:1-2, “Do not judge, or you too will be judged. For in the same way you judge others, you will be judged, and with the measure you use, it will be measured to you.”

“I just ask for people to please not go judging us without getting to know us first,” she said. “Leave the judging to God.”



THIRD ANNUAL MS. WHEELCHAIR KANSAS

SEARCH FOR CONTESTANTS

It's that time again! The Ms. Wheelchair Kansas Program is currently searching for women of achievement, who are wheelchair mobile, to serve as contestants in the Third Annual Ms. Wheelchair Kansas event. The 2007 event will take place on March 9-11 at the Holiday Inn Holidome in Topeka. Applications must be postmarked by January 7, 2007.

If you know of anyone who is interested in participating in our program, please forward this information on to them. Also, please feel free to send this information out to any of your list serves. Please visit our website at www.mswheelchairkansas.org for an application and an in depth look at our program.

FAMILIES TOGETHER, INC. ANNUAL INCLUSION AWARD

NOMINATION INFORMATION

The Inclusion Awards are presented annually to recognize administrators, teachers (general and special education), parents, siblings, self-advocates (youth with disabilities) related service personnel, para-educators, businesses, individuals and organizations that have successfully included people with disabilities in education, employment, and leisure activities.

To enter a nomination, please include on a separate sheet of paper, the name of the nominee, with complete address and telephone information, your response to the questions below and your contact information, with complete address and telephone information. Please include examples of what the individual/group has done that demonstrates their inclusive practices. Please complete a separate sheet of paper for each individual nominated. Nominations should be 250 words or less and may be e-mailed to leia@familiesTogetherinc.org; faxed to (913) 287-1970 or mailed to Inclusion Awards, Families Together, Inc. 1333 Meadowlark Lane, Suite 103, Kansas City, KS 66102. The deadline for submitting a nomination is January 16, 2007.

Helpful Hints in Nominating: Be specific and concise. Judges will be looking for exemplary illustrations of how inclusion has worked in your school and/or community. Simply holding disability awareness fairs or exposing people to community activities does not exemplify inclusion efforts, unless its part of a broader strategy showing results.

MS. WHEELCHAIR KANSAS NAMED 2ND RUNNER-UP IN NATIONAL COMPETITION

TOPEKA, Kan. – The 2006 Ms. Wheelchair Kansas (MWKS) was recently named the 2nd Runner-Up in the national Ms. Wheelchair America competition. Ranita Wilks joined with 27 other “Women of Strength” vying for the opportunity to represent women who are wheelchair mobile in the United States. This annual event was hosted in Little Rock, Arkansas and was held July 31 – August 6 at the Peabody Hotel. After an intense week of competition, networking, and empowerment, Wilks came away with great memories and the title of 2nd Runner-Up in the nation.

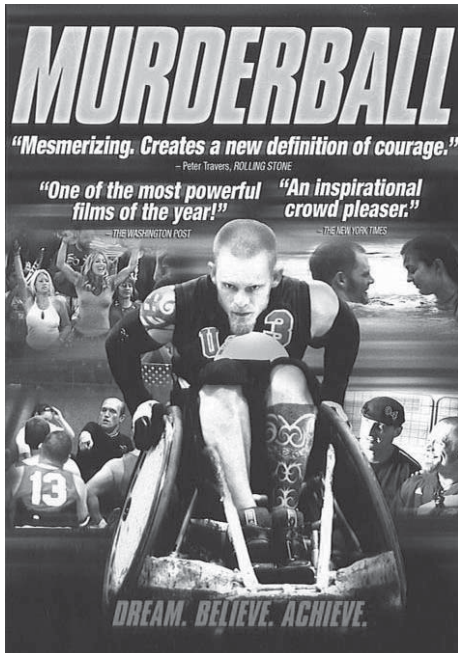
Wilks is the third woman to represent the state of Kansas at the national competition since the creation of the Ms. Wheelchair Kansas program in 2004. While in Little Rock, Wilks participated in two personal interview sessions where she was scored based on her accomplishments, self-perception, communication, and projection skills. She also gave a speech on her chosen platform, “Career Development Opportunities for People with Disabilities,” and heard from community speakers on a variety of topics. Wilks was able to enjoy some fun activities as well. All 27 titleholders were able to visit the Arkansas Historical Museum. They also attended a trade show and participated in a state gift exchange, as well as themed dinner nights, followed by social time and dancing. All activities followed the overall theme of “Women of Strength.” The week culminated in the crowning ceremony, which was held Saturday, August 5, where Autumn Grant of Massachusetts was named Ms. Wheelchair America 2007. The proceeding top four contestants were announced as follows: 1st Runner-Up- Rebecca Bierwolf of Utah; 2nd Runner-Up- Wilks of Kansas; 3rd Runner-Up- Emily DeBray of Alabama; and 4th Runner-Up- Phaedra Marriott of Missouri.

Wilks, of Lawrence, was crowned Ms. Wheelchair Kansas in March of 2006. Since receiving her title, she has worked to fulfill the MWKS mission, which is to educate, advocate, and empower all people on a state level. Wilks has attended many events and public appearances, as well as spoken to a variety of groups from elementary to college students, from the general public to community professionals. She has participated in variety of community fairs, two local parades, the Topeka Arthritis Walk, and has attended Independent Living Day at the Capital, the Big Tent Coalition Rally, the Youth Leadership Forum, the Lawrence ADA Celebration, and much more. Wilks is currently meeting with women across the state, that are wheelchair mobile, to obtain feedback on important issues and concerns in various areas. She has already held two “Tea with the Queen” brainstorming sessions and will continue these throughout the state in the coming months.

Wilks will continue to fulfill the MWKS mission in the coming months and is available for speaking engagements and appearances. For more information, please contact Carrie Greenwood, State Coordinator, at (785) 267-5982 or via email at mwheelchairkansas@yahoo.com. More information can also be found on the Ms. Wheelchair Kansas web site at www.mswheelchairkansas.org.



MOVIE REVIEW



MURDERBALL DVD REVIEW by Liz M

If you would like to watch a riveting movie that was nominated at the Academy Award 2006 Independent Film category, and you like the full-contact sport of Rugby, then Murder Ball is the movie to watch. The Rugby players are Quadriplegic, whether by car accidents, fist fights, gun shot or rouge bacteria, these men are forced to live life setting down. This is their version of the full-contact sport of Rugby. This movie is filled with action and suspense at the highest level. Murder ball, is a Rugby game with men who have the courage to play the game in custom-made gladiator-like wheelchairs for the disabled. This is a fast moving game that will hold your undivided attention and leave you wishing there was more. If you would like to see this movie we have the DVD available to check out at the CILSWKS office.

ANN COWLES THE VIOLIN PLAYER

COURTESY OF NEW MOBILITY MAGAZINE

Statistician Ann Cowles credits her violin for helping her through an awfully rough time. "I was misdiagnosed, lost my job, I was homeless, all these things," says Cowles, 44, correctly diagnosed with MS in 2001. "But I had my violin with me and I slept with it like a teddy bear."

When she was working again, Cowles, who lives in Colorado Springs, Colo., Began studying folk music for fun, until she lost the use of her left arm. She'd pass by her violin and pray, "God, if you give me my left arm back, I promise I won't play for myself anymore. So then my arm came back and I started playing in nursing homes." Thus began her professional music career.

Once, while driving from a performance, Cowles felt overtired and overheated, so she parked under an apartment building's awning to cool off. "I feel like I'm dying and this lady taps on my window and yells, 'You're in my parking space! Get out of there right now!' I couldn't explain – there was no way to explain to this woman," says Cowles.

Now she's developed a sticker alerting others that the person in the car is heat sensitive, and if found parked under shade of any type, will leave as soon as she cools off. For more info about the sticker e-mail Cowles at createspiritmusic@gmail.com.

BOARD MEMBERS WANTED

The Center for Independent Living SW KS is looking for Board members in western Kansas. Expenses for you to participate will be reimbursed. Visit our web site www.cilswks.org for a job application and/or see next page for the job description.

Continued on p. 6

Are you a person with a disability who uses the assistance of another person for work tasks?

We want to talk with people with disabilities across the United States who have experience using personal assistance services (PAS)* at work.

Our goal is to improve information about PAS in the workplace and to identify what works.

If you are interested in participating in this project or want more information about it, please contact *InfoUse*

Phone: 510 549-6520
E-mail: workplacePAS@infouse.com
2560 9th Street, Suite 320
Berkeley, CA 94710

*Examples of workplace personal assistance services (PAS) include readers and interpreters, help with lifting or reaching, re-assignment of non-essential duties to others, or other kinds of help to perform work tasks. Workplace PAS may also include help with eating, drinking, or accessing the restroom while at work.

Center for Personal Assistance Services

Sponsored by the
US Department of Education
National Institute for Disability and Rehabilitation Research
Grant #H133B031102

InfoUse is a subcontractor of University of California, San Francisco

OFFICES RELOCATING

SW KANSAS AREA AGENCY ON AGING

The Southwest Kansas Area Agency On Aging office in Lakin will relocate to Garden City on November 29, 2006.

New address: 1809 E. Mary, Suite 6, Garden City, KS 67846.

New phone number is: 620-275-4500

New fax number is: 620-275-4522

SOCIAL SECURITY OFFICE

The Social Security Office will be relocating starting Thursday, November 30, 2006. They will Open in the new location on Monday, December 1. Phone numbers and Zip Code will not change.

New Address: 2204 Summerlon Circle, Dodge City, KS 67801

BOARD OF DIRECTORS JOB DESCRIPTION

Title: Member of Board of Directors

Term: 3 years

Reports To: Board President/Chairperson

Purpose: To serve on the Board of Director as a voting member; develop policies and procedures for the operation of the organization; to monitor finances of the organization; to provide overall direction to the organization and its program; and to monitor the quality and effectiveness of services.

Meeting Attendance:

- Attend meetings as scheduled.
- Attend committee meetings if member.
- Attend board retreats, trainings, and other board activities.
- Attend and participate in special events as needed.

Obligations of the Board:

- Establish by-laws
- Create policy
- Select, supervise, evaluate, and dismiss Executive Director
- Secure adequate funds
- Maintain and update long-range plans

Specific Duties:

- Attend all board and committee meetings and functions, such as special events.
 - Be well informed about the organization’s mission, services, policies, and program.
 - Review agenda and supporting materials prior to board and committee meetings.
- For a complete list of duties please visit our website.

POOR CARE MANDATES CHANGE

Submitted by Frederick M. Markham, PhD

A month ago, I was in the Hutchinson hospital for 10 days. I was diagnosed with diabetes and contact pneumonia.

I am disabled and have a speech impairment. To my surprise, all but one nurse could understand me because mainly because she took the time when the others just looked at me and went on about their business. One time, a nurse came in to put an IV in my arm, and I told her I had to go the bathroom, she told me, "Hold on and will go get a nurse's aid to attend to you." An hour later, she came back to take IV out of my arm, and I said, "Do you remember I had to go to the restroom, but never mind now, it's too late". She said, "I will get a nurse's aid to help." I waited for another hour and by that time it was time for dinner. The nurse's aid came in to put me in my wheel chair so they could feed me. I asked them, "What's the matter with the nurses?" And continued to tell her the whole story. She told me, "That's what wrong around here, nobody tells us anything." She then apologized.

What's wrong with the Hutchinson Hospital? I have heard of many horror stories come from that hospital. In my opinion, they need more education on how to take care and communicate with patients. I know of several people who won't go there. I know I won't go anymore, I'd rather go the mortuary, I'd get better care.

MERRY CHRISTMAS & HAPPY NEW YEAR

CHRISTMAS AND ME

BY FRAN

Just because I have disabilities
Doesn't mean it's difficult to buy me holiday gifts

I may look different than you
My want, my needs, what I desire maybe few

So don't guess, don't wonder, please ask me
Get to know me, be my friend and you will see

When I am around,
please don't ask the other person what I want for Christmas
Talk to me acknowledge my presence

Don't assume you know the gift I'd want
Don't wonder; don't guess what I may wish for

I may be the only one who knows best what I want and need
Treat me how you want to be treated, not like a kid

Ask the person who knows me best, me
Just give me a chance to communicate my want, you will see
Quit treating me like a dummy

