OVER 1,000 UNITE IN THE NAME OF SELF ADVOCACY!

SABE’s national conference brings self advocates to KC

Over 1,000 people were jazzed up when SABE’s national conference came to Kansas City September 23-26, 2010! Jazz it Up: Feeling the Music of Self Advocacy was the theme of the 2010 National Advocacy Conference!

Self advocates from over 40 states as well as Guam and Canada came to Missouri to learn more about how self advocacy can grow stronger, self advocates can live more self-determined lives, and how relationships can improve the lives of people with disabilities.

The 2010 conference was a special date because it marked SABE’s twentieth birthday as well as the twentieth anniversary of the Americans with Disabilities Act. SABE KC 2010 celebrated the past, present, and future of the self advocacy movement. Sharon Lewis, the new commissioner of the Administration on Developmental Disabilities; Ari Ne’eman, the president of the Autistic Self Advocacy Network; and Mark Funkhouser, the mayor of Kansas City, were just a few of the big names that stopped by to visit the celebration.

On Thursday night, there was a birthday celebration for SABE’s birthday and the ADA. Our very own Joe Wrinkle, who served on the original SABE board, teamed up with Bill Story (KS) and Tia Nelis (IL) to teach the crowd about the history of the movement and get everyone jazzed up for the weekend! On Friday morning, ADD Commissioner Sharon Lewis gave a keynote speech on self-determination. Then, James Gardner, Liz Weintraub, and Nancy Ward joined together to present on how people can live more self-determined lives through having plenty of social capital. On Friday night, people were nominated for the SABE board. After Saturday’s elections we found out who was elected to SABE’s new board and executive committee.

People First of Missouri and the Self Advocate Coalition of Kansas teamed together with support from the UMKC-Institute for Human Development (UCEDD) and the Missouri Planning Council to plan SABE KC 2010. People First of Missouri and its partners are very proud of its work and will have a lot to brag about for the next two years until the next national conference!

To learn more about the conference and to view photos, memories, and more, visit http://sabekc2010.org.
Happy New Year Everyone!!!

We have moved from the season of giving to the season of cutting... commonly known as a legislative session at the tail end of an economic recession. There will be lots of issues with spending this year. It looks like it will be a difficult year and everyone will see some form of cuts. It is more important than ever to go to the Capitol, call your legislators or write them a letter. The legislators have a difficult challenge this year with the budget, and it is our job to help them see the people who are impacted by their decisions instead of just the numbers. You are the expert on you, and your story is valuable. I encourage you to contact those who represent you and share your story. Be confident. You do not have to have the answers. They have the numbers and people that help them figure those things out. What they do not have is a face to put to those numbers and a story to remember.

Roger Crome, Vice President of PFMO

SAVE THE DATE!

March 9th, 2011 at the Capitol in Jefferson City hundreds and hundreds of advocates will converge to educate their legislators about the rights of people with disabilities for the 10th Annual Disability Rights Legislative Day.

Please mark your calendars and plan to attend!
We asked self advocates what respect means to them and here’s what they said:

Respect means people letting you speak and not interrupting you! Like the golden rules: treat others as you want to be treated-- nice and polite.

Bobby, Lebanon, MO

If you treat someone the way you want to be treated, they’ll treat you the same way.

Robert, Sikeston, MO

Means being talked to and treated like a normal person because we are all people first, with or without a disability.

Larry, Joplin, MO

Respect to me means that people don’t talk back or be mean to me and that they like me just the way I am. They say if you want to be respected, you have to give it to everyone first.

Yisenia, Kansas City, MO

Means others, with or without disabilities, should always be treated the same: with respect.

John, Marshall, MO

Being treated like others and not being put down just because you have a disability.

Tim, Sikeston, MO

Respect means being treated with kindness and dignity and being treated my own age.

Margie, Kansas City, MO
Two issues ago, self advocate Mike Bishop told us about his plans to get out from under guardianship. We’re pleased to publish this update. Congratulations, Mike!

In 1982, I had a car accident that caused my disability. In 1984 after my father’s death, people thought I would need someone to look after me, so I was appointed a guardian. With that, I lost my legal rights. All of them. My guardian had to sign off on everything. I was not allowed to vote, or to get married. I couldn’t even share my story with you, without my guardian’s permission.

For over 20 years I’ve lived in Columbia, where I came for independent living. It’s an accessible town with supports and services. My guardian for many years – a Public Administrator – lived 120 miles away. Still, basically, my decisions belonged to her. Sometimes I’d connect myself to services. I found Boone County Family Resources on my own, just stopped by their office at Paquin Towers – but my guardian had to approve my plans and sign off on everything. She was the main decision maker at plan meetings about my life. A couple years ago a new Public Administrator was elected and became my new guardian.

Last year, I went to an “Alternatives to Guardianship” training sponsored by the Missouri Planning Council, Missouri Protection and Advocacy, and People First of Missouri. It made me want to get out from under my guardianship and win back my rights. An attorney from Protection and Advocacy helped me get ready for my court hearing. I had to go to a psychiatrist and get a statement – he said he felt I was able to make decisions for myself. My support staff from Life & Work Connections knows me and they know I don’t need a guardian, so they had information about my ability to make decisions. We convinced a judge that I don’t need someone else to make decisions for me. I know where to go for help if I need it. I’ve been on my own for a long time.

I have my rights back.

Questions about guardianship?
Want help understanding your options?

Check out the
Missouri Guardianship Project: A Resource Guide
at http://mofamilytofamily.org or call 1-800-444-0821!
People First of Boone County is teaching journalism students about People First language. So far we’ve taught four classes. We show our PowerPoint and then take questions from the students. We’ve reached about 650 students. Two of the classes were huge. Some of the students are already reporters, others will be some day.

We feel it’s important to get the word out to the journalism students. We’re tired of seeing newspaper stories and hearing reports about “the handicapped.” We tell the students there are two ways to segregate people with disabilities – one way is to put them in a building a close the door. Another way is with language.

Language can label and segregate. Language can hurt. We talk a lot about the R word. You’d be surprised how many students raise their hands when I ask them if they’ve used the R word. They just don’t realize how the word makes me and others feel. My own brother called me that when I was a kid.

We tell them if you’re writing or speaking about a person with disability – mention disability only if it matters – and if it matters, USE PEOPLE FIRST LANGUAGE. One time Jeff won an award for his volunteer work in Columbia. He tells the students about reading in the newspaper about the “disabled man” who won the award. “That man was me,” he says. “How about ‘Columbia man wins’?” he asks them. It’s like, if you’re writing about someone’s accomplishments, then write about their accomplishments. Why label them “disabled”? And that’s what we mean when we say language segregates people.

One of our members, Rene, recently had a seizure on a downtown sidewalk. An article came out in the paper describing her as a “victim” who had “suffered” a seizure, and about the good Samaritans who came to her rescue. She says it does make sense for the reporter to mention her disability in a story like that, but she says epilepsy is something that is part of her life as a person. She’s not a victim. She thinks it could have been a good opportunity for the reporter to write about what to do when someone has a seizure. That’s the type of thing we’re teaching the students. --Written by Jason Mize, PFBC
Chapter Updates

Take the time to read about the work of our local People First chapters. These are great examples of the work of our different People First chapters across the state!

Boone County  People First of Boone County continued its work in teaching reporters and students about people first language (see Jason’s article this issue).

On December 10 we joined with Columbia Parks and Recreation in holding a dance. Lots of people came and we raised over $400. Vice President Jeff Johnson was the DJ. This was our 9th year co-hosting the winter dance and it was the best ever.

We are proud of our friend Mike Bishop (see Mike’s article on page 4 this issue), for getting out from under his guardianship. We nominated Mike for the Personal Advocacy Award, given each year by Services for Independent Living. He won!

Independence  People First of Independence has continued to learn and share with each other as we try to keep up with the events in the state that affect people with disabilities. We have spent much of our meetings discussing these issues, particularly our efforts to close Habilitation Centers. Three of our members attended the SABE National Conference and enjoyed the experience very much. We have also enjoyed some good social time together. We had a picnic and cook out in September and then ended the year with a Christmas party and gift exchange. We were happy to have some members back for this meeting that had not been with us for a while. That was a special Christmas gift for the Independence Chapter! We are looking forward to making more progress next year.

Jefferson City  Jefferson City People First has not met for a couple months because our advisor had hip surgery. He is doing much better now. Our chapter now has fifteen members. One of our members and a long-time Special Olympian, David Fuhr, is now coaching a church league called Upward Basketball.

The new session started on January 5, 2011. We have been talking about the new legislators and the importance of educating about disability issues and testified. We attended 5,000 Shoes at the Capitol and Roger and Becky Dickey made the front page of the newspaper!

We hope to see many of you on March 9, 2011 for the 10th Annual Disability Rights Legislative Day!

Kansas City  People First of Kansas City has been meeting every month and is growing with new members. The Kansas City chapter also has new officers! Scott Trickey is our new president, Carrie West is our new vice president, Margie Olson is our new secretary, Lorie Perdieu is our new treasurer, and David Wills is our new Sergeant at Arms. We are trying to recruit more members and focusing on building new goals for the group. We are very proud that we completed the first grant year of People Planning Together.
**Lake Area**  In December, we held a Christmas Dinner and gift exchange. Some of the things we have discussed working on in the future are assisting the Arc of Missouri at 5,000 Shoes in the Capitol Rotunda. We have volunteered to stuff envelopes for that day. We also hope that many from our chapter will be able to attend and give our support and share our views.  

Also in December, our area Senate Bill 40 Board gave out awards at their annual Christmas Party, one for support staff of the year and one for self-advocate of the year. Several were nominated for each position as we have many excellent support staff in this area and many self advocates that continue to strive to improve their lives and the lives of their peers by advocating on their behalf. Of course both winners are associated with our local People First Chapter!  

We are having fire and safety training in the future and one of our members wants to assist others by teaching them some simple dance moves.  

**Lebanon**  We’re trying to get used to the cold, but it isn’t fun! We just finished our Pizza Hut fundraiser and it was successful. We’re going to wait until the summer to try it again. We’re planning our fun activities for February, including our annual Valentine’s Day party. If any one would like to come, it is at First Congregational Church in Lebanon. If any one needs directions, you can call at: 417-532-7383. We are also planning a bowling party. We’re still looking for new members. We’re wishing all a very Happy New Year!

**Rolla**  The Rolla chapter has been doing a christian T-shirt fundraiser in preparation for the next state conference. We met with our SB40 Board to insure our grant for another year. We had dinner with our November business meeting and a gift exchange and light snacks with our December meeting--a good time was had by all! We adopted a family for Christmas we bought gifts and food for a meal and delivered it on the 23rd. We are expecting a challenging new year for people with disabilities, with our People First brothers and sisters we are ready for the challenge.  

**Sikeston**  Our People First Chapter has been very busy this fall! We had seven members attend the SABE Conference in September! Everyone who attended had a fun time and brought back lots of information about their experience. Sikeston’s annual Cotton Carnival parade was held October 2 and our chapter was able to again be in the parade thanks to an Eagles Club friend and Morlan Dodge. Our Halloween party was October 29 at the Shrine Club in Sikeston. Members brought refreshments for the party and also provided the music! Our Thanksgiving Dinner was held during our November meeting! Everyone brought food to eat! Our annual Christmas Party was held December 12 at the Sikeston Eagles Club!
**Chapter Updates**

**Springfield**  The members of the Springfield Chapter of People First are really excited about their progress in 2010. In July we elected new officers: President- Marisa Clary, Secretary- Scott Wheeler, and Treasurer- Frank Collins.

We are working really hard to get out into the community and speak with people about the importance of being an advocate for themselves or others with disabilities. We have had such opportunities at several community events in 2010 and are hoping for more in 2011. We just finished a candle fundraiser to help defray the cost of operations.

**St. Joseph**  Our group has new officers: Chris Fagan-Chairperson, Gayle Crawford- Vice-Chair, Tammy Courter-Treasurer, Ida Kuehn-Secretary, Chris Overman-Sergeant of Arms, Gary Clouser-Steering Committee Rep. and Sara Shisler-Alternate Steering Committee Rep.

Seven advocates from our chapter attended the SABE Conference. The group had a great time and learned a lot about living independently.

People First had a Cookie Walk booth at the MERIL Fall Social. We also participated in Ringing the Bell for the Salvation Army. This is the sixth year the group has participated with this community activity. The group rang the bell for six hours. Chris Fagan said “It feels good to give back to our city.”

We held our Holiday Potluck Party. The group provided ham and turkey, the members provided covered dishes. We had 25 attend. We all ate until we thought we would pop! We played games and had a White Elephant gift drawing.

**Non Emergency Medical Transportation News!**

Anyone who has MO Health Net can get a ride to the doctor from NEMT. You might be able to get help with gas costs if you have a car or friend that can take you to your appointment. This has to be approved in advance by NEMT. You can get bus passes if you can ride the city bus if approved in advance. Call 1-866-269-5927 five days before your appointment to get approved. Sometimes you may have to have a note from your doctor to get this service. You will need to pay $2 for each trip. You have the right to be treated with respect and dignity. You have the right to privacy and you can exercise your rights without being afraid about the way NEMT programs will treat you.

*By Chris Fagan and Gary Clouser, St. Joseph People First*

This information is available at http://www.dss.mo.gov/mhd/participants/pages/medtrans.htm
Envisioning the Future: Envision 2010 Summit

Cathy Enfield of Independence is the treasurer of People First of Missouri. She is also a regional representative on the board of Self Advocates Becoming Empowered (SABE). Cathy was invited to participate as a panelist at the Envision the Future Summit held in Denver, Colorado on December 5 and 6, 2010. Here’s what she had to say about the experience:

There were six of these meetings held in different cities around the United States during the last two months. The meetings were sponsored by the Administration on Developmental Disabilities and were organized and championed by Commissioner Sharon Lewis.

The purpose of these summit meetings was to gather and prioritize grass roots input and information about the issues and problems that affect people with developmental disabilities and possible solutions to them that might involve the ADD either directly or indirectly to implement.

This information will be used to help plan the future of the ADD both in the development of their five year plan and other long term goals and also as part of the process to draft the concepts and language for the Reauthorization of the Developmental Disabilities Act.

This is the first time in the fifty year history of the ADD that a grass roots information gathering process such has this has ever been done. It was especially significant because of the emphasis by Commissioner Lewis and her staff on making the meetings inclusive and the special efforts they made to not only include self advocates but to pay close attention to their input into the process.

I spent several weeks before the meeting gathering input and information from disability organizations in Missouri and from self advocates and other disability advocates. I was able to share this information with the group in the prioritization process.

I learned a great deal from these meetings and she was honored to have been invited to be part of this historic process!

Check it out: You can submit a testimony online too! The Administration on Developmental Disabilities invites you to share your vision of the future! To join the conversation online, visit http://www.envision2010.net!

Envisioning the Future: Allies in Self Advocacy

PFMO officers have been invited to participate in a really exciting summit about self advocacy in partnership with the Administration on Developmental Disabilities, Network of DD Councils, State P&As, and UCEDDS. This summit will take place in April in Kansas City, Mo. The purpose of the summit, one of a series of five regional summits being held across the United States, is to move the self-advocacy agenda forward by getting everyone working together at the local, state and federal levels.

For more information, stay tuned for the next issue of Message of the People!
PFMO Steering Committee Meeting - March 2 & 3, 2011 -- Jefferson City, MO


Don’t forget to vote!
Next election: April 5, 2011