

# INSTEP



The biannual Step Out USA, Inc. newsletter for our board, advisory board, members, friends, and patrons

WINTER/SPRING 2011

## The Dignity of Risk:

Message from our Executive Director, Patricia Coy

### WHAT IF...

- What if you never got to make a mistake?
- What if your money was always kept in an envelope where you couldn't get it?
- What if the job you did was not useful?
- What if you took the wrong bus once and now you can't take another one?
- What if you could do part of the grocery shopping, but weren't allowed to do any because you weren't able to do all of the shopping?
- What if your only chance to be with people different from you was with your own family?
- What if you never got to make a decision?
- What if you had no privacy?
- What if the only risky thing you could do was act out?
- What if you grew old and never knew adulthood?

### WHAT IF YOU NEVER GOT A CHANCE?

— Linda Stengle, *Laying Community Foundations for Your Child with a Disability*

As you read this edition of INSTEP it will be easy to see that Step Out continues to achieve its mission of creating social, cultural and educational connections for adults with learning disabilities. The 2011 Calendar is one of the best ever and has our members attending outstanding cultural events and visiting some of Chicago's oldest and diverse neighborhoods. But what you may not realize from reading INSTEP and reviewing the calendar is that we are also allowing our members to experience the "dignity of risk" and practice self-determination.

Robert Perske in "Hope for the Families" states that overprotection may appear on the surface to be kind, but it can be really evil. An oversupply can smother people emotionally, squeeze the life out of their hope and expectations, and strip them of their dignity. Overprotection can keep people from becoming all they could become. Many of our best achievements came the hard way. We took risks, fell flat, suffered, picked ourselves up, and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try. Adults with learning disabilities need these chances too.

The chance to make your own mistakes and suffer the consequences is called the "Dignity of Risk."

We are talking about prudent risks and that is what Step Out events provide for our members. Members are not expected to face challenges without the assistance to decide which choices are prudent and which are not. This self-determination, the ability of a person to consider options and make appropriate choices, is a skill that adults with learning disabilities need help to acquire. In *The Dignity of Risk: One Father's Perspective*, Larry Finkelstein writes that as parents and professionals, we may develop an "invalid mindset." We may become so fearful that they will hurt themselves or others that we build an invisible protective bubble around them denying the feeling of independence that we as adults cherish.

Parents and professionals have found clever ways of building avoidance of risk into the lives of adults with learning disabilities. Now we must work equally hard to find the proper amount of risk they have the right to take. Over the past six years as I have observed our membership I have learned that there can be healthy development in risk taking and crippling indignity in safety. Step Out professionals and parents need to continue to assist our membership to experience the "dignity of risk", learn from their mistakes and move on to self-determination!

## Rockin' around the Christmas Tree with the Rockin' Docs

There was a doctor in the house, in fact there were **five doctors** in the house, at Step Out USA's 7th Annual Holiday Party on December 5, 2010 at Maggiano's Little Italy in Skokie, Illinois. If a sumptuous Italian Buffet wasn't enough, sixty-one party-goers including members, their guests/family, Step Out staff and board members "Rocked Around the Christmas Tree" to the sounds of the Rockin' Docs.

Lead singer Dr. Ken Stein, plastic surgeon, was joined by band members Dr. Mike Weisman, podiatrist and guitarist; Dr. Al Saxon, general surgeon and percussionist; Dr. Rob Wilkin, dentist and vocals; Dr. Fred Duboe, OB/GYN, vocalist and guitarist; Jeff Rutter and Paul Wood, keyboard, guitars and vocals with the Cryan Shames; and Rocky Penn, vocals and drummer with the Cryan Shames and the



Left to right: Paul Wood, Jeff Rutter, Mike Weisman, Rocky Penn, Ken Stein, Al Saxon, Fred Duboe, and Rob Wilkin.

Buckingham's provided an afternoon of vintage Rock and Roll for Step Out members as well as a trip down memory lane for their parents. Founded in 1985 by Dr. Duboe, the group often donates their time and talent to not for profit organizations whose mission they encourage. Members and their families will long remember the best Step Out party entertainment ever. In addition to "oldies" like *Taking Care of Business*, Dr. Stein's rendition of *Blue Suede Shoes* and *Secret Agent Man* were unforgettable crowd pleasers!

A SPECIAL THANK YOU TO THE ROCKIN' DOCS FOR A FESTIVE CLOSE TO A GREAT YEAR!

## Move Over Roger Ebert...Introducing Step Out Flick Friends' Movie Critics

When Maria Lagios, Step Out Board President, and Pat Coy discussed the possibility of starting another Member Facilitated program, the movies seemed to be a perfect fit.

"As both Executive Director of Step Out USA and Director/ Owner of TranSteps, I am in a unique position observing personal growth and social maturation of many of our members in a variety of settings. Ivan, Michael, Dan and Andrea have worked with me in TranSteps since 1991 and that's how long they have been reviewing and recommending movies to me," explained Pat Coy.

Combined with their shared love of movies and their demonstrated ability to work cooperatively it was evident they could handle the job and serve as role models for other members. Ivan, Dan, Andrea and Michael will work together as Member Contacts planning movie outings for Step Out members and then posting their reviews on the Step Out website. These outings will be in addition to Step Out monthly events, seminars and Culture Vulture events. Anyone who is already a Step Out member and has both internet access and an e-mail address is welcome to join Flick Friends. For more information call the Step Out voice mail at 847-289-4480.



## New Staff Joins Step Out USA

**Kara Rhodebeck** joins our staff as a new facilitator. Kara is presently working on her Bachelor Degree at DePaul University. In addition to her academic responsibilities she serves as a volunteer at Bottomless Closet and as a tutor/ mentor for children at the Marshall Field Garden

Apartment Homes/ Neighborhood Network Technology Center. At Marshall's she creates a weekly educational lesson plan focusing on art, drama, and music therapy. Kara has a background in small business administration. She ran her own catering service in her hometown of Canton, Ohio before enrolling at De Paul University.

*"I am very excited to be part of Step Out USA. I took this position because I thought I could learn from each person involved in Step Out and I could put my energetic, people-oriented personality to work! I hope to be open, warm, and welcoming so that members will feel comfortable talking and sharing with me. It is human nature for people to seek interaction and friendship and Step Out is assisting those who may have more difficulty than others in social situations."*

In her spare time she enjoys concerts, plays volleyball, and "attempts" to complete the Sudoku and word searches in the Red Eye.



Left to right: Dan Minow, Andrea Lagios, Michael Sangston  
Lower right: Ivan Fenster

## Steppin' Up

- Congratulations to Megan Durkin and James Slattery on their marriage!
- Jill Sick is running a marathon in Disney World on January 7, 2011.
- Five members of Step Out have completed computer class at Leeds Council: Dan Minow, Michael Sangston, Christine Barr, Andrea Lagios and Matt Palmore.
- Christina Barr and Jim Pinto attended dress rehearsals of two Lyric Opera productions, *Un Ballo in Maschera* and *Mikado* as guests of Mrs. Gene Anderson.

## ADHD and Genetic Implications

Over many years, there has been a large controversy concerning causes of ADHD. Many clinicians and researchers had implicated a variety of environmental factors such as nutrition, pollution, azo dyes and other substances as causes for ADHD. Others insisted that the cause is largely a genetic defect. On September 30, 2010, the internationally respected British Medical Journal, **Lancet**, published the results of a study titled: *Rare Chromosomal Deletions and Duplications in Attention Deficit Hyperactivity: A Genome Wide Analysis*.

Since large rare chromosomal abnormalities (deletions and duplications) known as Copy Number Variables or CNV's have been implicated in neurodevelopmental disorders, this study undertook a genome wide analysis of CNV's in 410 children with ADHD and 1,156 unrelated matched controls who met criteria for ADHD but not schizophrenia and autism. The findings showed that large rare CNV's were identified in these children with ADHD. An increased rate of rare chromosomal abnormalities was particularly high in those with intellectual disability. A second study of 825 patients with ADHD and 35,243 matched controls found that the CNV's identified in ADHD were significantly present in both autism and schizophrenia.

The findings provide genetic evidence of an increased rate of chromosomal abnormalities. This suggests that ADHD is not merely a social construct but has a significant genetic component. The results of this study are important. Parents with ADHD children are often encouraged to attempt costly and time consuming treatments involving scientifically unsubstantiated modalities without any obvious improvement. This research confirms that environmental modalities are not responsible nor can significantly alter ADHD.

## Making a Difference: One Parent at a Time

One of the greatest challenges for a small not for profit organization is raising funds. The financial health of an organization such as Step Out USA is of utmost importance not only to provide the services necessary to its members and to expand the membership into geographical areas where they are needed, but to also employ and maintain the most competent and enthusiastic staff to provide these services. Large organizations are supported by government as well as private grants and personal donations. International exposure and publicity draws attention to their cause and facilitates fund-raising. A recent startup such as Step Out USA does not have the exposure to attract such financial support and consequently depends primarily on personal contacts and fund-raising events.

Parents have consistently come to the rescue in supporting fund-raising for Step Out primarily through individual donations. One parent undertook a personal fund-raising

campaign which generated a much needed cushion for Step Out to function successfully during this widespread recession.

Phyllis Gottlieb, mother of member Steven Gottlieb, enthusiastically undertook the task to personally contact friends and acquaintances to solicit donations for Step Out USA. She inspired other relatives to do the same. This effort was enormously successful and serves as an effective way for parents and relatives of our members to make a substantial contribution enhancing the experience of our membership. Her example has set a precedent which has inspired other parents to do the same. Step Out assists with all the bookkeeping, acknowledgments, stationery and organization. Phyllis is willing to help you get started with your personal campaign. Contact her at [pgottlieb17@hotmail.com](mailto:pgottlieb17@hotmail.com).

## Step Out Members PLAYED their way to a Healthier Brain!

On July 17th ten Step Out members participated in a unique game event at Marbles: the Brain Store in Skokie, Illinois. Marbles offers products to stimulate and strengthen the brain, ranging from scientifically-acclaimed software and books, to simply fun games, puzzles and activities. Products fall into five key brain functions: critical thinking, memory, word skills, visual perception and coordination. Before entering the Marbles collection, products are reviewed by a board of Brain Health Experts that consists of scientists, physicians, psychologists and other therapists to ensure their brain strengthening affect.

Our group chose to focus on the areas of critical thinking, memory and visual perception while playing Smart Mouth, Sherlock and Spot It! Christine Barr and Andrea Lagios also gave their eye-hand coordination a workout by testing their skill with the OgoSport Mezo Disk, a floatable, portable flexible game that helps relieve stress by bouncing balls up to 150 feet off mini trampolines.



Left to right: Michael Sangston, Danny Minow and Larry Ziegler working together at the Brainstore.

Research shows that the brain has the ability to generate cells throughout life. Participating in new and challenging activities can help adults with learning disabilities maintain and improve cognitive function. Challenging themselves to solve a puzzle, memorize trivia or strategically move a game piece stimulates brain cell growth.

**Many thanks from everyone at Step Out USA to advisory board member Brian Israel who designed the 2010 Holiday Card!**

## Stimulating Review and Update for Parents and Professionals

Step Out USA was privileged to have Dr. Lisa Stanford as guest speaker at our annual Parent Professional meeting on Sunday, September 26, 2010. Dr. Stanford is Associate Professor of Clinical Psychiatry directing Pediatric Neuropsychology clinical and training programs at the University of Illinois. She has published, taught and conducted research on the neurobehavioral aspects and cognitive effects of Learning Disabilities, ADHD, Autism and Traumatic Brain Injury. She is a past member of the Learning Disabilities Association.

Dr. Stanford discussed the particular characteristics of learning problems in individuals with ADHD. Because there is overlapping of symptoms between Learning Disabled, ADHD and Autism, it is essential that an accurate diagnosis be conducted by a qualified specialist in order to determine which therapy will be the most beneficial to the patient. A correct diagnosis also has important implications when applying for employment, insurance and other benefits. Dr. Stanford and other qualified specialists have the procedures, knowledge and the experience to work effectively in these areas. While testing and evaluation is essential in the early years, it is often considered unnecessary for adults. Dr. Stanford explained through her succinct and enlightening presentation of brain mapping that adults have very clear patterns which can be analyzed for deeper clarification and medical intervention.

She discussed the genetic involvement as one of the important causes of ADHD. Her studies corroborate the recent research presented in the British Journal of Medicine confirming genetic abnormalities rather than environmental factors as the major cause of ADHD.

Dr. Stanford's breadth of knowledge in the field of Learning Disabilities and ADHD and her ability to communicate it to parents and professionals was quite impressive. It was enlightening and encouraging for all parents present to consider investigating evaluation at the adult level to insure that the latest in accommodations are provided for adults with learning disabilities. Medical interventions as well as behavior modification can greatly influence the life of the individual in the family and performance on the job. It was clear to everyone present that family members with a history of ADHD, Pervasive Developmental Delay, and Traumatic Brain Injury would benefit by a current analysis to chart effective therapy and management of the syndrome. Dr. Stanford can be contacted at [Istanford@psych.uic.edu](mailto:Istanford@psych.uic.edu).

### Here's how to join STEP OUT...

**Step Out USA** members come from all parts of the Chicagoland area for friendship, recreation, and education. We're always looking for NEW members. For more information, call Dr. Patricia Coy at (847) 289-4480.