

DSACK

Down

Syndrome

Association of Central Kentucky



WHAT'S GOING DOWN WITH DSACK

VOLUME III – NUMBER II

MARCH-APRIL 2009

NEWS FROM THE E.B.

The DSACK Executive Board will now have this standing column in the newsletter to increase our communication with the DSACK Community.

• EB HAS LOFTY GOALS AND IS STRENGTHENING SOLID FOUNDATION

The DSACK Executive Board has been diligently working with a strategic planner, and has been working hard to create a solid foundation for DSACK. One of our most important goals is to establish a "sustainable DSACK" by working to solidify processes, procedures and structure that will support our lofty goals and aspirations. We are moving forward and expanding in virtually all areas of our organization.

In 2008, our highly successful "2nd Saturday New Parent Group" continued to grow and host monthly speakers, and we accepted a practicum student from UK who developed the new "Teen/Young Adult Group". We also managed to revamp the "New Parent Packets" and maintain a relationship with local hospitals to help distribute these. In addition to carrying out a successful "Piggy Bank" fundraiser and community awareness campaign, we created new and impressive DSACK brochures and note-cards, as well as a DVD of our DSACK community, and we began our annual "Appreciation Day". We also received a grant to fund our innovative Birthday Card project, and have implemented several "Everyone Counts" type presentations within the community. We also were able to obtain non-profit mailing status. On the horizon, we have many other irons in the fire such as: continuing collaboration with a highly-qualified web designer who is donating the cost of the website development and maintenance; creating a group for our elementary aged children, and our Birthday Card project which is in the works. Our newsletters continue to receive outstanding feedback and comments, and the editor of "Lexington Family" magazine liked it so much that he asked an Executive Board Member to write a personal piece for a magazine that is being distributed state-wide with a 25,000 person circulation. DSACK was also

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ADVISORY BOARD MEMBERS

Executive Committee members plus:

Caroline Boeh Baesler, Parent

Karen Roof Boudreaux, Parent

Sandra Brock, Cabinet for Health and Family Services, Executive Director of the Ombudsman

Carolyn Bay, M.D., Chief, Division of Clinical/Biochemical Genetics & Dysmorphology, Dept. of Pediatrics, UK

Belva Collins, Ed. D., UK Special Ed. Professor

Harold Kleinert, Ed.D., Exec. Dir. Of IHDI

Becky Lesch, Parent

Dixie Miller, Parent, Developmental Interventionist

John Riley, M.D., Pediatrician at PAA

Meg Steinman, Parent

with Tops Products, has a wonderful husband (Eric, her high school sweetheart!) and 2 beautiful daughters. Laney is almost 5 and Joella, who has Down syndrome, is 18 months old. The family has been in Central Kentucky for almost 10 years and "can't think of a better place to raise our daughters", says Lee Ann.

Lee Ann graduated from the University of Southern Indiana, Evansville, IN, with a BS degree in Accounting. She has nonprofit accounting experience from working at the Boy Scout Council in Indiana and at USA Equestrian here in KY.

Even though Lee Ann is employed full time, she is able to work from home 3 days a week so she can be with her girls. When asked why she wants to serve DSACK in this way, she said "I feel very strongly in the purpose of DSACK and felt that the outreach from this organization to my family was so beneficial and I give them credit for how far we have come with our journey since being blessed with Joella. I have wanted to find a way to serve, and hopefully by lending my bookkeeping skills I can help in that capacity. I feel very blessed to be a part of such a wonderful group of people. I'm excited about our journey together and hopefully make a difference in the lives of our children who are beautiful, capable, loved and so much more."

The DSACK board welcomes Lee Ann with gratitude! Thanks for donating your time and expertise, and for always sharing a smile with us.

• DSACK IS GOING TO DC!

Down Syndrome Affiliates in Action will convene in Washington, D.C., February 25-28. At this time, there are over 80 affiliate groups from across the nation registered to attend, and DSACK is one of them! A few of us will be arriving Wednesday evening in time for a legislative briefing and will then travel to Capitol Hill on Thursday to meet with Senators McConnell and Bunning, and Congressman Chandler.

We will attend sessions all day Friday as well as Saturday morning and will return home Saturday afternoon. There are over 46 sessions offered, usually 8 sessions concurrently, so we hope to divide and conquer by deciding which sessions will most benefit DSACK. We invite you to check out the website at www.dsaia.org and see what kind of tough decisions are ahead of us in regard to choosing these sessions! We are in the midst of formulating a strategic plan for DSACK for the next 2-3 years, and most of the goals and objectives

we have set will be discussed at this conference. Our purpose in going is ultimately to enable us to sustain and grow DSACK and make our organization stronger and more useful to all of you. We are excited about the future of our beloved DSACK, and will be anxious to come back and implement all that we learn!

• "APPRECIATION DAY": EB WOULD APPRECIATE SOME HELP PLANNING IT!

The Executive Board will soon be planning our 2nd annual Appreciation Day. Our inaugural event last year was very well attended and we would love some help planning this year's event! Call 859-494-7809 if you could lend a hand.

WORKING TOWARDS BUDDY WALK 2009: DSACK NEEDS VOLUNTEERS!

(submitted by Regina Schmutte)

We are starting the pre planning for the 2009 Buddy walk, which will take place on October 3rd at Keeneland. We are so excited about the walk this year and hope to increase our sponsors and donations to hit a record amount!! If you know of, or have any sponsorship opportunities, please contact Regina. We are also looking for volunteers to be a part of a Buddy Walk Committee. So if you have some time, and want to give back to DSACK, please call Regina Schmutte at 859-983-3754 or email her at remicale2@aol.com. Let's all join together to make this the best Buddy Walk ever!!

We would like to thank the following people for stepping up and taking on one of the most difficult tasks of the Buddy Walk,

REGISTRATION COMMITTEE: Meg Steinman and Dixie Miller will co-chair the committee, and Julia Ruzzene and Kate Steinman will serve as committee members!

CATERING COMMITTEE: Becky Lesch Chair

We are still looking for the following volunteers for the following areas:

VOLUNTEER COMMITTEE Chair and Members, this committee will be responsible to procure volunteers for all aspects of the walk, i.e. set up/clean up, food stations, registration, etc...

FUND RAISING COMMITTEE Chair and members, this committee will be responsible for securing sponsorships from all previous sponsors and new sponsors.

DOOR PRIZES COMMITTEE Chair and Members, this committee will be responsible for securing donated "give a ways"

ENTERTAINMENT COMMITTEE Chair and Members, this committee will be responsible for securing entertainment for the day of the walk

MARKETING AND PR COMMITTEE Chair and Members, this committee will be responsible for public awareness and marketing materials for the walk

EXHIBITOR COMMITTEE Chair and Members, this committee will be responsible for securing exhibitors, as well as their needs for day of the walk

• BUDDY WALK VOLUNTEER CHERISHES LIFE MORE FULLY NOW

(Submitted by Madelyn Crawford, student)

Thank you for your support, Madelyn! Because of youth like you, DSACK is able to celebrate that ALL people are beautiful, capable, and loved!

Becoming a volunteer at the annual Buddy Walk has to be the most meaningful experience of my life. I started volunteering for the Buddy Walk in the 8th grade when a family friend, whose child has Down syndrome, asked if a group of us from my school could come help out. When we got there the group I was with was assigned to work with a group of adults who had Down syndrome; so two of us got paired with one person with Down syndrome. Spending time and working so closely with the people who were affected with the Down syndrome really opened my eyes and helped me to realize all that I have and that I need to appreciate all of it; but even more than that they helped me to see that life is meant to be fun and not everything is to be taken too seriously. When I saw how much joy they got from dancing to the music, going to look at a fire truck or ambulance, eating pizza, and just doing the walk I learned that it is the little things that we see every day in life and take for granted that can make us happy. I now know that I need to cherish those every day moments, and make the most of every day because that is how life is to be lived, I try my best to live in the present and not worry too much about the future and do what I can today to make the future more enjoyable. Now every year I look forward to going to the Buddy Walk, spending time with the buddy I am given to watch for the day, and hopefully making their day and mine a day of fun and enjoying all that life has given us.

LOCAL NEWS TO USE

• A CAMP EXPERIENCE FOR INDIVIDUALS WITH DOWN SYNDROME

The Center for Courageous Kids (www.courageouskids.org) is a "world class medical camping facility in the rolling hills of Scottsville, KY, providing a cost-free, safe, and fun camping experience for serious ill and disabled children and their families." They are offering

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highlighted in the "Southsider" recently as a wonderful organization for volunteers in the community to get involved with and "Give Back".

As you can see, the Executive Board is quite busy with DSACK and we look forward to communicating with you our many successes and our genuine excitement for the future through this new column in the newsletter! PLEASE CONSIDER STEPPING UP AND GETTING INVOLVED WITH DSACK TO HELP DSACK CELEBRATE THAT ALL PEOPLE ARE BEAUTIFUL, CAPABLE AND LOVED!

• DSACK TREASURES OUR NEW TREASURER!

Lee Ann Mullis has agreed to take on the role of treasurer for DSACK, replacing long-time treasurer Ellen Fernandez. We are so excited that Lee Ann is willing to donate her time in this way! She works full-time as a Consignment-Inventory Analyst/Accountant



LEE ANN'S DAUGHTERS
JOELLA AND LANEY
THIS PAST HALLOWEEN

a "Family Retreat Weekend on March 27th-29th for individuals with Down Syndrome and his/her family. They are also offering a Summer Camp opportunity for children ages 7-15 with Down syndrome on June 22-25th. Visit their website to complete find out more details and complete an application: <http://www.courageouskids.org/> or call 270-618-2900.

• REGISTRATION FOR MIRACLE LEAGUE IS HAPPENING NOW

The 2009 Spring Toyota Bluegrass Miracle League will begin registering for its spring season February 1. Registration forms are available under the player link on the website. The season will run from April 11 through May 16 on Saturdays. The cost is \$40 per player and financial assistance is available for those who qualify. Volunteers will also be needed to serve as buddies for the spring season. If you need more information, you can visit <http://www.bluegrassmiracleleague.org/> Or you can contact Kevin Haury at 863-4841 or kevin@bluegrassmiracleleague.org.

• THERAPEUTIC RECREATION FUN CAMPS THIS SUMMER: REGISTRATION COMING IN APRIL!

The camp, which is designed for all youth and young adults with disabilities between the ages of 5 – 21, will be held at Castlewood and Woodland Parks. The camp will operate from 7:45 am – 4:30 pm, Monday – Friday. The Castlewood Camp is open to ages 5 – 12 while the Woodland Camp is open to those 13 – 21 years. The cost is \$200 per session and scholarships are available. Campers who qualify for free lunch through their school may be eligible for a reduced camp fee. For more information on TR Fun Camps, call (859) 288-2928. The camp sessions are: Session 1: June 15-26; Session 2: June 29-July 10; Session 3: July 13-24

• WISHES DO COME TRUE: A SISTER'S PERSPECTIVE

(Submitted by Hannah Brewer, sister to Emily Brewer. Hannah is nine years old and in the 3rd grade at Veterans Park Elementary. She won the PTA "Reflections" Contest in literature for this piece! Congratulations to Hannah and thanks for being so special!)

Emily's Wish

Hi! My name is Hannah Brewer. I have three sisters and one brother. One of my sisters, Emily, has Down syndrome. Although she might look a little different she is capable of doing just about anything you can do. That is what I've been telling people all my life!

Emily loves riding horses at Central Kentucky Riding for Hope (CKRH) and playing in a baseball league called the Bluegrass Miracle League. Both of these are societies where



HANNAH & EMILY WITH MICKEY & MINNIE AT DISNEY

children with disabilities can do activities just like you and me! Now, isn't that a great idea? Well, I think so considering how much Emily loves it! Another thing she likes to do in her free time is watch movies. I would say that is Emily's very favorite

thing to do! She especially likes the Disney movies. Emily likes to act these movies out, although she has never been to Disney World! And that is where my story begins.

Have you ever heard of a foundation called Make-A-Wish? Since Emily has special needs she qualifies. Not only does Emily have Down syndrome, but she also has had heart surgery and hip surgery! But those are just two of her major surgeries. Over all she has had about sixteen surgeries. She is one tough cookie! So she qualifies for a wish from this foundation in all sorts of ways! At first my parents didn't know what to ask for. Then it just like popped out at them, (is what I've been told). Emily's wish should be to go to Disney World!

At first I had no idea any of this was going on! Then one night on our summer vacation we were out at a restaurant, it was our last night in South Carolina. I guess Mom and Dad thought it was time to tell us that two women from Make-A-Wish were planning to come to our house that upcoming Friday to meet us and do some paperwork with us. When we got settled at our table we got the big news. After Mom explained it all to us, I said, "Well how are we going to get there?" She held up her hands in a plane shape and twirled them around, which is sign language for airplane. I was so excited! I wanted to stand on my head and start screaming! Literally! I held my hands cupped over my mouth so I wouldn't scream! I don't think Emily quite understood this whole experience, so my dad came in and explained it to her. While he talked, all I could see on Emily face was a big grin rising.

That next Friday two ladies from Make-A-Wish did come, and before they said anything else they handed out gifts! I watched as my mom and dad went through reading this and signing that. After all the paper work was done, they told us the only thing that would keep us from going would be the date! We decided we should go over Christmas break. We should leave for the airport the morning of December 30. We still weren't 100 percent sure we were going yet. But we were 99.9% sure! The ladies also said we would get either a coming-home party or a going-away party.

Now listen to this! The foundation told us there will be more surprises along the way! This certainly is a lot for an eight-year old like me! I think it is very exciting for the whole family!

I can't wait for Disney World! I am very excited about going on a plane! I have never flown before! I am also looking forward to seeing the Electric Light Show Parade at Disney World.

After reading this paper, don't you just feel like saying WOW?



TWO BEAUTIFUL PRINCESSES AT DISNEY

• WISHES DO COME TRUE: A MOTHER'S PERSPECTIVE

(Submitted by Traci Brewer, Mother of Emily and Hannah)

Well, thanks to the wonderful people at Make-A-Wish, Emily did get her wish to go to Disney.

On Dec. 29, all seven of us boarded a plane for Florida and Disney World. We were so excited!

Not only was it Emily's wish, but also a wish for all of us. You see, throughout her short lifetime, Emily has had 15 surgeries, and we have another major surgery on the horizon for this summer. Needless to say, this made it impossible from a health standpoint, and quite frankly, a financial standpoint for us to take our five children to every child's dreamland. Let me take just a moment to tell you how incredibly proud we are of our children. Never, ever, have any of our children complained about the sacrifices that have been necessary since Emily's birth. To be honest, they are all so incredibly in love with Emily, I don't think they even recognize that they are making sacrifices. They have always pitched in to help, love and support not only Emily, but each other as well. That being said, it was this mother's dream-come-true to have all of my children enjoy this vacation.

Make-A-Wish made this whole experience so incredibly easy and pain-free! They came to our house to meet all of us, bearing gifts for the younger children. They stayed in constant contact with us to make sure we had everything we needed and all of our questions were being answered. They even provided a gift card for us to purchase luggage! They

arranged everything from plane tickets, lodging, rental van, spending money, and a special dinner with the Disney princesses. They provided a three-day pass to Disney, two-day pass to Universal, and a pass to Sea World. You would think that was way above the "call of duty". But no! Upon our return, they invited our friends and family to attend a welcome-home party complete with a princess cake and balloons! This organization is more than amazing!

Do you think they put us up in just any hotel? Goodness no! We stayed at a very magical place called Give Kids the World. This amazing place was built just for families sponsored by wish foundations. Families from all over the world and all fifty states have stayed here. Every family is provided a villa with all the comforts of home. Ours was even decorated for the holidays, as was the whole campus. This magical place has a gingerbread house that serves three full meals a day; an enchanted castle with a carousel, wishing well, books, toys and games; two swimming pools; putt-putt golf; a train for children to ride; a huge model train city; and a brand new life-sized Candyland playground. How much does all this cost? You guessed it! Everything at Give Kids the World is free to wish families. As if that isn't enough, they will even deliver continental breakfast items, pizza, and cookies right to your door. It takes 1000 volunteer hours per week to run this wonderful place. Most of these volunteer are senior citizens that volunteer their time to bring joy to all of these families. It is impossible to tell you how warm, loving and caring every individual was to our family. Their sole purpose is to make sure you have a vacation of a lifetime.

We have been so humbled by this experience. To know that these organizations exist to make a child's wish come true and allow that child's family to enjoy a time away from the

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Celebrations

* This note is from an out-of-town DSACK family whose child was recently hospitalized in Lexington. The EB was able to negotiate an extremely discounted rate at Springhill Suites near UK campus for the family. The family was also given a stipend from DSACK to help with expenses. Fortunately, their child is now home and on the road to recovery. Here is a portion of the note they wrote:

"DSACK, we are eternally grateful for all you have done for our family...from a wonderful place to stay (rest), assistance with financial needs and prayer support. Our lives have been truly blessed. Your organization has proven faithful to assisting those meeting the challenge associated with Down's. Thanks again for your care, concern and compassion."

A "SHOOTING STAR" ON THE BASKETBALL COURT

Check out this inspirational story about Patrick, a high school senior basketball player in Maine who happens to have Down syndrome. Go, Patrick! <http://www.msnbc.msn.com/id/21134540/vp/29030653#29030653>

Have something you want to celebrate? An award, birthday, or some other achievement? Email submissions to Courtney Elbert at celbert@roadrunner.com with "Newsletter Item" in the subject line for inclusion in the newsletter.

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THE BREWER FAMILY AND PRINCESSES AT DISNEY

daily worries and stress that so often make up the days of families with chronically-ill children. We laughed, we played, we stuffed ourselves with junk food, we stayed out late every night, and we truly enjoyed every minute together! While we may never remember every single moment of this wonderful vacation, we will NEVER forget the extraordinary people that worked to make not only Emily's wish, but our whole family's wish, come true! God bless them all!

• DSACK LENDING LIBRARY

CONTACT NICOLE MAHER AT 859-881-5423 OR NICJOE@ROADRUNNER.COM

- All items are available to check out for a one month period.
- Items can be shipped to your home & returned the same way
- Multiple copies of most books are available
- Please let us know if there is something you would like to see added to the DSACK collection

BOOK TITLES

- Ability Development from Age Zero
- America according to Connor Gifford
- Angel Behind the Rocking Chair
- Babies with DS, A New Parents' Guide
- Building a Joyful Life with your Child who has Special Needs
- Classroom Language Skills for Children with Down syndrome
- Communication Skills in Children with DS
- Count Us In Growing Up with DS
- Differences in Common
- Early Communication Skills for Children with DS
- Final Gifts ~ Understanding the special awareness, needs and communications of the dying
- Fine Motor Skills for Children with DS
- From the Heart
- Gifts, Mothers Reflect on How Children w/DS Enrich Their Lives
- Gross Mother Skills in Children with DS
- How to Give Your Baby Encyclopedic Knowledge
- How to Teach Your Baby Math
- Incredible Edible Gluten Free Food for Kids
- Infinity Walk, Preparing Your Mind to Learn
- Kids with Celiac Disease
- Married with Special-Needs

Children

- Medical & Surgical Care for Children with Down syndrome
- More Than a Mom
- Special Children Challenged Parents
- Teaching by Design
- Teaching Children with DS about Their Bodies, Boundaries and Sexuality
- Teaching Math to People with DS and Other Hands-On Learners
- Teaching Reading to Children with DS
- The DS Nutrition Handbook
- Uncommon Fathers
- What to do About Your Brain Injured Child
- Wings to Fly, Bringing Theatre Arts to Students with Special Needs
- Views from Our Shoes

DVDs/VCR

- Discovery - Pathways to Better Speech for Children with DS
- What Did You Say? A Guide to Speech Intelligibility in People with DS
- Guide to Child Management, Parent Education Series
- Guide to the Parent Teacher, Parent Education Series
- Guide to Learning Disabilities, Parent Education Series
- DVD and Compendium for NDSC 2008 Conference

2ND SATURDAY NEW PARENT GROUP: AN INVITATION TO JOIN!

The 2nd Saturday New Parent group meets on the 2nd Sat. of each month from 9-11 a.m. It is for parents whose children with DS are birth-5 years of age. Childcare provided. Contact Michelle for more information at 859-223-4207 or mandmgilliam@windstream.net.

• LETTER FROM A FELLOW "DOWN SYNDROME" PARENT

Dear New Parent,

You just learned that your child has Down syndrome.

This usually surprising news comes just at the time in your life when you have experienced one of life's greatest joys - the birth of your child.

I know that the news that your precious baby has Down syndrome can bring on a range of emotions and lots of questions.

I know this because our daughter Megan has Down syndrome and my wife Mary and I have been where you are right now.

One of the things that has been most helpful to our family in responding to the unique challenges of being a "Down Syndrome Parent" is joining the DSACK New Parents group.

Our monthly meetings are very casual and we usually have a speaker providing helpful information topics requested by the parents. And, it's been very helpful to share experiences and the support of parents who are traveling the very same road.

No commitment is necessary, just give us a try.

I hope to see you there!

God Bless,

*Scott Mandl
Richmond, KY*

PS. After 15 months, Megan surprises and enchants us every day.

We love her so much and can't imagine her being any different.

That's her with Santa below...



TEEN/YOUNG ADULT GROUP

DSACK's Teen/Young Adult Group meets once a month typically, and if you are interested in getting involved, please use the contact information at the end of Megan's letter here. Megan is a self-advocate who has Down Syndrome. Currently, Megan is enrolled in an associate degree program at the community college so that she can become a certified



BROOKE, MEGAN AND TROY AT GEORGETOWN COLLEGE BASKETBALL GAME WITH TEEN/YOUNG ADULT GROUP

occupational therapy assistant. In addition to her volunteer time observing Occupational Therapy sessions at a private Occupational/Physical Therapy/Speech Clinic, she is now employed there part time and learning skills as an office assistant. Last but not least, she enjoys a full extra-curricular schedule, including competitive cheerleading and swimming with Special Olympics, playing the piano, and learning life skills, such as cooking and managing her check book in readiness for independent living!

• AN INVITATION TO JOIN: "WORKING TO CREATE GREATER SOCIAL INVOLVEMENT AMONG YOUNG ADULTS WITH DOWN SYNDROME"

I believe the Down Syndrome community is in need of greater social involvement opportunities for young adults. To have more social outlets is not only healthy, but provides the chance for people to learn from one another. A greater sense of community, belonging, and friendship is important to everyone.

Ideally, a group or club would be created to offer such opportunities. Members of the organization would take trips to various locations, volunteer with younger children with Down Syndrome, or simply gather at one another's homes for luncheons. Recently, a group of young adults went to see the movie Bolt at the Movie Tavern and visited an apple orchard together. Also, my parents and I hosted a luncheon for the group at my home last weekend.

Interacting with this group of young people has allowed me to meet new faces and form new friendships. Spending time with my peers is very important to me. Being with the group gives me some time for fun and the chance to speak with others like myself. I am looking forward to seeing what's next.

If you are a teenager or young adult with Down Syndrome, you should join our group! Please contact me (meganchandrika@yahoo.com) or Brooke Reed (brooke.reed@uky.edu or 's 321-507-0332) if you are interested!

• TEENS AND YOUNG ADULTS: YOU CAN DANCE IF YOU WANT TO!

On Friday, April 3rd, The UK CATS Dance will be held in the Grand Ballroom of the Student Center from 7:00 - 9:30 pm. The mission of the dance is to establish meaningful, lasting one-to-one friendships for teens and young adults with intellectual disabilities and their typical peers.

There will be escorts for every guest as well as snack foods, music, and games. We will also be having UK athletes and the Wildcat mascot at the event taking pictures with fans and just having fun!

To RSVP or more information on the "UK CATS Dance," guests can contact Barb Jackson with UK Student Government at bajackson5@gmail.com or (630) 664-2617

To RSVP include: Name of guest and guardian, Telephone number, Address, Email address, Organization he/she is a part of, and whether he/she is traveling with the organization to the UK CATS Dance.

NEWS & INTERNATIONAL NEWS

• NDSS EN ESPANOL

NDSS is proud to announce the launch of our Spanish website! Please visit ndss.org and click on the blue button, NDSS En Espanol, or visit <http://esp.ndss.org/> to link automatically!

• THE DSACT EDUCATOR PACKET

"Working Together to Educate and Include Students with Down syndrome", a compilation of best practices, is the first comprehensive tool for parents and educators in Texas which provides up-to-date information on educating children with Down syndrome in inclusive settings with their typically developing peers. Parents of children with Down syndrome are still being told by school districts, even today, that their child can't be included in regular kindergarten or first grade, can't go to art or music class, can't eat lunch in the cafeteria with their peers, can't be taught to read or write. These settings are where students with Down syndrome have a legal, moral and human right to be, but still many are excluded. Now, educators in Central Texas have a resource to help them do the right thing. Now, parents can arm themselves with the Educator Packet and march into school conferences to say, "Yes, it is possible to educate my child with his or her typically-developing peers, and here is how."

Adopted by Austin Independent School District as a joint training manual, it will form the basis for ongoing trainings for educators throughout the region, and unlock the school doors for hundreds of students with Down syndrome.

Rounding out its focus to improve the quality of education for members with Down syndrome, the DSACT education committee has also developed a

parent packet of helpful information for parents and are implementing "Parents and Schools in Partnership" (a collaborative effort between school districts and DSACT, originally implemented in Kansas City), an inclusion newsletter for educators and "The Learning Program" (a literacy and mathematics educational program from the Down Syndrome Foundation of Orange County).

To download a copy of the packet, visit:

<http://ndss.org/images/stories/NDSSresources/2008%20educatorpacket.pdf>

Or contact: Down Syndrome Association of Central Texas ~ 3710 Cedar Street, Box 3 ~ Austin, TX 78705 ~ www.dsact.com ~ (512) 323-0808

• "HOW'S YOUR NEWS" AIRING ON MTV

The NDSS plugged this show so I felt comfortable that they endorsed it, but I wanted to watch it personally before mentioning it in our DSACK newsletter. I have to admit I was skeptical when I discovered that MTV and the dudes involved with "Southpark" were behind the scenes. I imagine there will be contrasting opinions about the show and I would like to publish some of these in the next newsletter. Please watch the show and share your thoughts about it by emailing celbert@roadrunner.com. Please keep responses to less than 350 words. If you wish for your comments to remain anonymous, please state that clearly on your submission. The following information about "How's Your News" comes from the show's website: http://www.mtv.com/ontv/dyn/how_s_your_news/series.jhtml

You've never seen a show quite like this before. First conceived at Camp Jabberwocky, the nation's oldest sleepover camp for people with disabilities, How's Your News? began as a series of short films with the members of the camp serving as reporters. The shorts caught the eye of Matt Stone and Trey Parker, of South Park fame, who offered to Executive Produce a feature film that followed the camp reporters on a road trip across America. The film was widely embraced by the disabled community, won several film festival awards and is now used as a training video for people with disabilities worldwide.

The 6 episode series consists of a team of reporters, in their customized tour bus, driving across America documenting their experiences, which includes everything from covering the red carpet at the Grammys and performing at the SXSW music festival, to learning to make cheese balls with Amy Sedaris in her apartment. During the course of the show, we learn more about this unique cast and their outrageous sense of humor through man on the street segments, musical

performances, behind the scenes adventures and celebrity interviews.

Since its inception in 1998, How's Your News? has built an enthusiastic cult following with the release of three previous documentaries and a CD of soundtrack music performed by the cast. The show enjoys the full support of the reporters' families as well as nationally recognized disability advocates and organizations. Earlier versions of the show, executive produced by Trey Parker and Matt Stone, have appeared on HBO/Cinemax, PBS and Channel Four England.

THE USE OF GINKGO, PROZAC AND FOCALIN AS A "TREATMENT" FOR DOWN SYNDROME

(This article may be found at <http://www.down-syndrome.org/statements/2106/>)

A combination of drugs recommended for depression and attention deficit and hyperactivity disorder is being widely promoted as a "treatment" for Down syndrome. There is no scientific support for the routine use of this protocol by people who have Down syndrome. It is important that families and healthcare professionals are aware of the lack of evidence for safety and benefits from use of this protocol.

We are a group of healthcare professionals, scientists and support organizations who care for and about people with Down syndrome. We wish to provide families with information about a proposed "treatment" for Down syndrome. We recognize that all parents wish to improve the lives of their children with Down syndrome and are interested in treatments, therapies and interventions that can help. We respect these wishes. At the same time, we are concerned that these "treatments" are potentially dangerous.

We are all aware of the advances that have been made in the basic science of memory and cognition in animal models of Down syndrome and are hopeful that these studies may lead to new ways to improve the lives of people who live with the condition.

Physicians and biomedical scientists evaluate potential interventions on the basis of safety and benefits to patients. As we describe below, the "treatments" that the Changing Minds Foundation recommends have not passed either test: there is no information whether these compounds are safe for children, especially young children. Furthermore, there is no evidence to support the claims for benefits that have been made.

Because we care about your children, we strongly urge families to consider this information when considering the claims for this "treatment".

THE PROTOCOL

An organization called the Changing Minds Foundation is promoting a "new treatment for Down syndrome" that leads to "life changing" results. The "treatment" includes regular doses of Fluoxetine (Prozac), Dexmethylphenidate (Focalin XR) and Ginkgo biloba, Phosphatidylcholine, 'Body Bio Balanced Oil' and folic acid. Some of these substances are associated with potential harmful side-effects. Some of these side-effects are of particular concern for people with Down syndrome and younger children.

Fluoxetine (Prozac) is used to treat depression, obsessive-compulsive disorder, bulimia nervosa and panic disorder. Dexmethylphenidate (Focalin XR) is used for the treatment of

attention deficit and hyperactivity disorder (ADHD). Their use should be initiated and monitored by an appropriately qualified physician and should be limited to applications and treatments formally reviewed and approved by appropriate governmental and medical drug regulatory agencies.

EVIDENCE OF EFFECTS AND SAFETY

There is no scientific evidence to support the use of any of this protocol with people with Down syndrome of any age in order to improve memory or any other aspect of cognition. Nor is there any evidence that this protocol is safe for routine use with people who have Down syndrome.

The few studies referenced in support of this protocol are studies of mice. These mice have been engineered to carry extra copies of some genes similar to genes found on human chromosome 21. (People who have Down syndrome have an additional copy of this chromosome). These studies may or may not be good indicators of aspects of memory and learning for people who have Down syndrome. Studies in mice alone are not sufficient to support use of this (or any) protocol in children or adults with Down syndrome.

The Changing Minds Foundation promotional videos do not prove the claims of benefit from the protocol. While the people shown are clearly doing well, none of the individuals shown are functioning beyond the wide range seen in others with the syndrome. Claimed changes following 'treatment' could be the result of many factors. Only a controlled trial can give clear evidence of treatment effects.

SCIENTIFIC PROGRESS

Scientific research has improved our understanding of Down syndrome considerably over the past 30 years. This has led to the better healthcare and education received by many people with Down syndrome today. Many scientists and organizations continue to work to improve our knowledge and understanding of effective ways to improve quality of life for people who live with Down syndrome.

Although the pace of further progress is often slow and this can be frustrating, only careful research and rigorous controlled trials can provide the evidence necessary to demonstrate that a therapy is useful and safe.

FURTHER INFORMATION

• Ginkgo

Although bilobalide, a component of Ginkgo Biloba, has been shown to be a GABA antagonist, the activity has been tested only in isolated cells and in only one subtype of GABA receptors. No controlled studies have been done in animals or humans to establish safe doses, or to prove the claimed benefits.

<http://www.nlm.nih.gov/medlineplus/druginfo/natural/patient-ginkgo.html>

• Fluoxetine (Prozac)

The action of fluoxetine on the growth of new nerve cells seen in one part of the brain of Ts65Dn mice has not been replicated in humans. Published case reports suggest that medications like Prozac used in pregnancy can harm the fetus. The potential impact on developing minds of babies and young children is unknown. A general, or uncontrolled, increase in nerve cell growth is not necessarily a good thing, especially over long periods of time.

<http://www.nlm.nih.gov/medlineplus/druginfo/meds/a689006.html>

• Dexmethylphenidate (Focalin XR)

The use of stimulant medication should be carefully considered for children with unusual heart structures, which includes about half of children with Down syndrome. Again, use is not recommended for babies or very young children.

<http://www.nlm.nih.gov/medlineplus/druginfo/meds/a603014.htm>

• Folic acid

Folic acid supplementation has been shown to have no significant effects for infants and children with Down syndrome on a range of developmental measures. <http://www.nlm.nih.gov/medlineplus/druginfo/natural/patient-folate.html>

<http://www.bmj.com/cgi/content/full/336/7644/594>

• 'Off label' use

Families and healthcare professionals should understand that use of the protocol at this time is essentially experimental, with none of the benefits of a controlled trial. Monitoring for adverse effects would be the responsibility of the prescribing physician, with no one collecting that information to determine real risks. Similarly, positive effects would not be collected in a credible way that could be used by healthcare professionals to gauge the value of the treatments. While there is no current evidence of the treatment's effectiveness for people with Down syndrome, there are significant risks of harm.

This statement is endorsed by the following scientists and clinicians:

- Roel Borstlap, Paediatrician n.p., Stichting Downsyndroom, The Netherlands.
- Sue Buckley OBE, Director of Science and Research, Down Syndrome Education International and Emeritus Professor of Developmental Disability, University of Portsmouth, UK.
- William I Cohen, MD, Developmental-Behavioral Pediatrician, Director, Down Syndrome Center of Western PA Children's Hospital of Pittsburgh of UPMC, Professor of Pediatrics and Psychiatry, University of Pittsburgh School of Medicine, USA.
- Sindoor S Desai, BDS, Cleveland, New York, USA.
- Jesús Flórez, MD, PhD, Professor of Pharmacology, University of Cantabria School of Medicine, Santander, Spain.
- Sallie Freeman, Ph.D. Professor Emeritus, Down Syndrome Clinic Advisor, Department of Human Genetics, Emory University School of Medicine, Georgia, USA.
- Edward J Goldson, MD, Pediatrician, The Children's Hospital, Aurora, Colorado, USA.
- Lilliam Gonzalez de Pijem, MD, Pediatric Endocrinologist, Puerto Rico Down Syndrome Association, San Juan, Puerto Rico.
- Joan E Guthrie Medlen, RD, LD, Vice President Down Syndrome Education USA, Director, Disability Compass, Publisher, Phronesis Publishing, Author, The Down Syndrome Nutrition Handbook.
- Rob Hanson, MD, PhD, Pediatric Cancer and Hematology Center, St. John's Mercy Medical Center, St. Louis, Missouri, USA.
- Michael M Harpold, PhD, Chief Executive Officer, Down Syndrome Research and Treatment Foundation, USA.
- Jacqueline London, Professor of Molecular and Pathological Biochemistry, University Paris-Diderot, Paris, France.
- Acislo M Marxuach, MD, Fundación Puertorriqueña Síndrome Down, San Juan, Puerto Rico.
- Philip J Mattheis, MD, Associate Professor, Cincinnati Children's Hospital Medical Center, Ohio, USA.
- William C Mobley MD, PhD, Professor, Department of Neurology and Neurological Sciences and Director, Center for Research and Treatment of Down Syndrome, Stanford University,

California, USA.

- David Patterson, PhD, Professor, Department of Biological Sciences, Eleanor Roosevelt Institute, University of Denver, Colorado, USA.
- Alberto Rasore-Quartino, Professor, Unit of Neonatology, Galliera Hospital, Genoa, Italy.
- David S Smith, MD, Program Director, Down Syndrome Clinic of Wisconsin Children's Hospital, Wisconsin, USA.
- Dr Renaud Touraine, CHU-Hôpital Nord, Service de Génétique, Saint Etienne, France
- Jeannie Visootsak, MD, FAAP, Assistant Professor, Developmental-Behavioral Pediatrics, Department of Human Genetics & Pediatrics, Emory University School of Medicine, Georgia, USA.
- Patricia White, MD, Chair, Board of Directors, Down Syndrome Research and Treatment Foundation, USA.

This statement is endorsed by the following organizations:

- Association Française pour la Recherche sur la Trisomie 21, France.
- Association of Parents and Friends of Children with Down Syndrome, Prague, Czech Republic.
- Centrul de Resurse Sindrom Down, Bucharest, Romania.
- Deutsches Down-Syndrom InfoCenter, Hammerhöhe, Lauf, Germany.
- Down Syndrome Education International.
- Down Syndrome Education USA.
- Down Syndrome International.
- Down Syndrome New South Wales, Australia.
- Down Syndrome Research and Treatment Foundation, USA.
- Down Syndrome Research Foundation, Vancouver, Canada.
- European Down Syndrome Association.
- Fundación Iberoamericana Down21, Spain.
- Fundación Síndrome de Down de Cantabria, Spain.
- National Down Syndrome Congress, USA.
- National Down Syndrome Society, USA.
- Stichting Downsyndroom, The Netherlands.
- Trisomie 21 France.

REMEMBERING DR. BILL COHEN

(www.ndss.org)

Dr. Bill Cohen, national leader in the Down syndrome movement and dear friend of the National Down Syndrome Society (NDSS), died on February 6, 2009. He touched the hearts of families around the country and was a respected colleague to all physicians who knew him. Dr. Cohen was serving on the NDSS Clinical Advisory Board.

As a developmental-behavioral pediatrician, Dr. Cohen was the director of the Down Syndrome Center at the Children's Hospital of Pittsburgh. He was the co-founder and co-chair of the Down Syndrome Medical Interest Group (DSMIG) which produced the seminal healthcare guidelines for all persons with Down syndrome, ages 0-18. He also co-authored the book, *Down Syndrome: Visions for the 21st Century*, published in 2002 on behalf of the NDSS. For all of these visionary efforts, he was given a Clinical Service Award by the NDSS in 2004.

His colleagues remember him best for his seemingly endless amount of joy, his eager willingness to share best practices, and his earnest belief that all people with Down syndrome deserve the best from their medical providers and society, at large.

In addition to his work on Down syndrome, Dr. Cohen was a leader in teaching and studying doctor-patient communication, family adaptation to chronic medical conditions, clinical hypnosis, and family therapy. He was a clinical member of the American Association of Marriage and Family Therapy, the American Academy of Pediatrics, the Society for Developmental and Behavioral Pediatrics, Ambulatory Pediatric Association, and the American Balint Society.

The world will continue to change positively because of Dr. Cohen's lasting impressions. The NDSS family misses him intensely and will be grateful to him forever.

DONATIONS RECEIVED

• This past December, Bluegrass Hospitality Group hosted a Holiday Fundraiser for various charitable organizations such as DSACK. During the month of December, they donated 20% of gift cards purchased in DSACK's name. \$1845 in gift cards were purchased in DSACK's name, and we received \$369! Our friends at BHG manage Malone's, Sal's, Oscar's, Aqua, and Harry's, so be sure to stop in when you are dining out.

• Paul Taylor and Family wrote the following note with a donation to DSACK: "Dear DSACK:

This past Christmas '08, in lieu of exchanging gifts with our extended family, we let each of our children choose an organization to donate money. Our son, Paul, chose to send money to DSACK in honor of our neighbor Sam Elbert. Thank you for what you do

• Joe and Vanessa Seitz and our friends at Brookdale Farm

COURTNEY'S MICHELLE'S CONTEMPLATIONS

Michelle kindly offered a contemplation for this newsletter. I was moved by her reflection and her perspective, and wanted to include it in this issue. Our loved ones with Down Syndrome, and the gentle souls of people they influence continue to teach us big lessons in life.

A Lesson for Mom

(Submitted by Michelle Gilliam)

My daughter is currently enrolled in the toddler program at Providence Montessori School. One of the teachers was absent all of last week because of her own sick child, so I tended to pick up Ava early when I could, to perhaps make things a little easier on the other 2 adults in the classroom. When I came to get her on Wednesday, she was saying her "goodbyes" when Victoria, a teenager who helps in the classroom, came over to Ava. Victoria is a sweet, gentle soul who, at naptime, would rock Ava to sleep in the dark "nap room" until Ava could fall asleep at school on her own. Well, Victoria leaned over Ava and pointed to her own nose, saying, "Ava, what is this?" I had a smile plastered on my face but in my head I'm thinking "Give me a break. She has known body parts for 2 years. You gotta be kidding me. Please, whatever you do, do NOT underestimate my child just because she has Down syndrome. She is quite capable of telling you that that is your nose." (I'm being honest with you all here because I bet you have all felt that way at some point. And there is a lesson here.) So, I'm still smiling, trying to give Victoria the benefit of the doubt because, after all, she is young. I'm waiting for Ava to tell Victoria that that is her nose, and show Victoria how brilliant she really is. So, Ava answers. In Spanish.

Yep, and proceeded to name the other body parts that Victoria pointed to. In Spanish. I don't know any Spanish. Victoria thought it would be fun that day to sit down and teach Ava some body parts in another language. Now, I ask you to examine the irony of this. Who was being underestimated? Who was blind to the Down syndrome? Who KNEW that Ava could do more and take it a step further? Who was jumping to conclusions? Who was downright wrong? This is by far my favorite Ava story. But it really isn't so much about Ava. It's about a sweet, gentle, intuitive soul who saw my little girl as someone who could do it. It's about a mom who learned a big lesson.

CALENDAR

SPRING 2009 SEMINAR SERIES

Human Development Institute at the University of Kentucky
The spring series will focus on issues of concern and advocacy relating to individuals with disabilities and their families. All seminars are offered at no charge and are open to the community.

All seminars will be held at the Human Development Institute's Coldstream #160 Training Room, located at 1525 Bull Lea Rd. We will also teleconference the seminars to HDI's other locations - Mineral Industries Building on UK's campus and the 7th Floor Conference Room at the KU Building in downtown Lexington. Please call (859) 257-1714 to ask that a registration form be faxed, mailed or forwarded electronically.

THE FUNDAMENTALS OF DISCIPLINE FOR STUDENTS IN SPECIAL EDUCATION: A POSITIVE BEHAVIORAL SUPPORTS APPROACH (DONNA WICKHAM, PH.D.)

March 6 - 1 to 3 p.m.

Preventing behavior problems before they occur is a key feature of Positive Behavior Supports. This session will describe the most effective interventions and detail responses before, during and after the problem behavior to reduce the chances of it occurring again.

COMPASS: COLLABORATIVE MODEL FOR PROMOTING COMPETENCE & SUCCESS (LISA RUBLE, PH.D.)

April 17 - 1 to 3 p.m.

This seminar presents a collaborative model for parents and teachers working with effective tools to improve outcomes and success for students on the autism spectrum.

SAFE AND SECURE: AN OVERVIEW OF ESTATE PLANNING: ISSUES FOR FAMILIES WITH CHILDREN WITH DISABILITIES

March 10, 2009 from 11:00 a.m. - 1:00 p.m.

Bryan Station High School, 201 Eastin Rd, Lexington

Estate Planning provides a great opportunity to think pro-actively about the future of one's child with a disability. Participants will develop a "to do" list that will help them develop a letter of intent and help prepare legal documents.

2ND SATURDAY (0-5) PARENT GROUP CANCELLED
Saturday, March 14

DSACK ADVISORY BOARD AND EXECUTIVE BOARD MEETING WITH DOROTHY BROWN, STRATEGIC PLANNER

Saturday, March 14

8:30-1:30 @ The Racquet Club, Crosby Drive, Lexington

2ND SATURDAY (0-5) PARENT GROUP CANCELLED
Saturday, April 11

Location and speaker TBA, childcare provided (If you are on Michelle's email list for parent group, you will be notified. If you aren't on this list and would like to come to the meeting, please contact Michelle at 223-4207 or mandmgilliam@windstream.net.)

BI-ANNUAL CONFERENCE: FIRED UP!

FOR DOWN SYNDROME IN TN

Friday & Saturday, April 24-25, 2009

Down Syndrome Association of Middle Tennessee presents a statewide conference on Down syndrome every other year.

Fired Up! for Down Syndrome brings together disability advocates, researchers, parents, educators and medical

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professionals for a two-day conference on a wide variety of issues related to Down syndrome. Past conferences have included workshops on Art and Music Therapy, Fitness and Weight Management, Educational Planning, Conservatorship, Sibling and Family Issues, Nutrition and much more. The conference also includes a portion for Self-Advocates, including presentations by and for individuals with Down syndrome on topics including employment, self-expression and conflict resolution.

If you have suggestions or questions regarding the 2009 Fired Up conference, email DSAMT at dsamt@bellsouth.net or call 615.386.9002.

FREE LUNCHSHOPS sponsored by the Fayette County Parent Resource Center in collaboration with the Bryan Station High School Youth Service Center, Bluegrass IMPACT East Office, the Commission For Children with Special Health Care Needs and the College for Technical Education.

The focus of the sessions are to provide information about a wide range of disability and non-disability topics to families of children with disabilities, agencies and school staff. To get more information call the Parent Resource Center at 859-381-4229.

To register for Lunchshops, call (859) 381-4229 or email stella.smith@fayette.kyschools.us or anita.jones@fayette.kyschools.us.

You may also register on-site at each session.

TRANSITION ISSUES WITHIN THE SCHOOL AND COMMUNITY

April 14, 2009 from 11:00 a.m. - 1:00 p.m.

College for Tech Education; 1165 Centre Pkwy #120

This Lunchshop will explore issues related to transition planning. All grade levels of transition will be discussed from elementary to high school to post secondary.

"YOU ARE AN IMPORTANT PIECE OF THE PUZZLE"

TRANSITION FAIR!

FITTING IT ALL TOGETHER: SUCCESSFUL TRANSITION FOR STUDENTS WITH DISABILITIES

Thursday, March 19, 2009, 9:00 a.m.—1:30 p.m.

UK Student Center, Lexington

The Central Kentucky Regional Interagency Transition Team is sponsoring a Transition Fair for 11th & 12th grade students with disabilities, parents, high school staff, post-secondary educators, and regional/state agencies in Kentucky. The purpose of this regional event is to connect students with disabilities and their families with successful post secondary opportunities. Over 20 informational tables and breakout sessions will be provided by agencies and central Kentucky businesses along with DOOR PRIZES!

For additional information and/or registration assistance, contact Christina Krantz at 859-257-4314 or Christina@cksec.org. Space is limited - Register Early Deadline March 13, 2009

THE 37TH NDSC NATIONAL CONVENTION

July 31-August 2, 2009
Sacramento, California

SUBMISSIONS

Want to submit information for inclusion in What's Going Down With DSACK?

Submission deadline for next issue is Wednesday, April 8th and can be sent to Courtney Elbert at celbert@roadrunner.com. Send us pictures of your family member who has T21 to be included in the banner of the newsletter. Digital photos are preferred. Photos should be of the individual alone – head & shoulders preferred.

Do you...

- know someone who might like to receive our newsletter?
- have an interest in placing an ad in our newsletter?
- want to receive the newsletter by e-mail instead of through regular mail to save DSACK mailing costs?

If so, please contact Courtney Elbert at (859) 879-2182 or celbert@roadrunner.com. Let's get the word out about DSACK and our loved ones with DS!

MAKING CONNECTIONS

THE PLAYGROUP!

If you are interested in being in a playgroup, please call Eileen Miot. She is flexible with days, times and location. Her little ones are almost 2 and 3 1/2 years old. Contact her to discuss! erwky@yahoo.com or 859-340-2771.