

Building a caring, understanding and supportive community open to all individuals and families whose lives include a person with Down Syndrome

Sweetheart Dance



The Down Syndrome Community's annual Sweetheart Dance was held at the Highland Center this year. Two days after St. Valentine's Day, festive DSC families and friends gathered together to dance, socialize and eat pizza. A wide range of youngsters attended the all-ages dance, from 8 months old to eighteen years old and beyond. Since pizza was provided, parents were able to head directly to the Highland Center without worrying about starving to death.

At six o'clock the dancing began when the KBSG DJ spun some heavy beats and several kids displayed their break dancing talents. Soon (after parents quelled the dangerous flailing of arms and feet) the dance floor settled into a nice groove while people arrived and settled in.



Later, the DJ drew parents and kids into a huge circle and led the Bunny Hop and the Hokey Pokey, then continued to play requests and hits from the 50's through 80's. Godfather's pizza arrived at seven o'clock with stacks of hot pizza. They say you can never buy enough pizza because people will eat as much as you provide, but there was enough to re-energize the dancers. Afterwards, the crowd enjoyed heart-shaped cookies and Valentine cupcakes donated by Albertsons.

Linda Michael provided the handmade decorations for the dance. Beneath red and white streamers, paper hearts and pink balloons, the DJ played a slow song for the mother/son and father/daughter dance. "This is the best dance the Down Syndrome Community has thrown," said one mother, eyes welling with happy tears.

Dances geared especially toward the younger kids included the limbo and the Hula Hoop dance. When the DJ lined everybody up and began to play the Macarena, the experts quickly shined, but the amateurs hung in 'til the end. The evening came to a close. New friends said good-bye and old friends hugged. "All of my kids are exhausted," said a beaming mother as she rocked her baby with Down syndrome. "This was a great time for all of us."

"People were a lot thirstier than I imagined," said Sean King, event coordinator. "We bought four cases of pop and six gallons of juice. It's all gone!" He vowed to provide more refreshments for the next dance – and more cheese pizza for the kids. "I learned a valuable lesson tonight," he said. "Kids prefer cheese pizza."

Girl Scout Troop 3165 of Burien volunteered to help set up the dance floor, serve food and clean up the inevitable mess afterward. "They really made it easy on us," said Linda Michael, event co-coordinator. "We're lucky to have their support."

The next dance is scheduled for the early fall.



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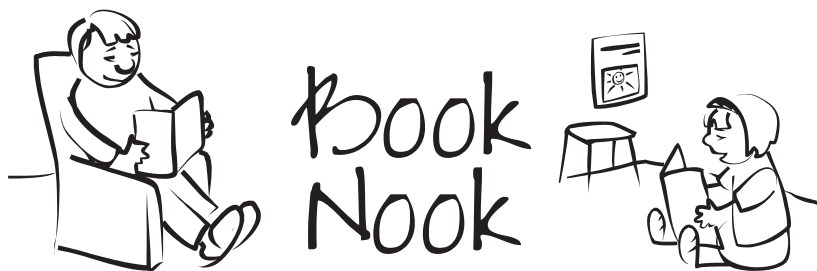
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Effective Teaching Strategies for Successful Inclusion: A Focus on Down Syndrome is a comprehensive resource guide for educators and parents. It provides facts and strategies on dealing with health, communication, cognition, behavior, curriculum adaptation and a host of other topics.

The book opens with a brief introduction to the medical facts of Down syndrome. This section is a perfect length to provide a teacher or caregiver unfamiliar with Down syndrome enough background and knowledge to be useful without too much detail, which might cause the reader to lose interest. Each subsequent chapter then deals with a different aspect of the education process. The authors point out how some typical characteristics of a child with Down syndrome often impact the educational area. The authors then go on to provide specific advice and ideas for how to improve or adapt traditional educational practices to maximize the learning potential of the child.

As an example the authors point out how small motor skill difficulties might affect learning math. If math is being taught primarily by having the student do problems on paper, the math lesson may turn into a printing lesson, leading to frustration. However, if the student can respond to questions by pointing to or circling their answers, or by some other method of response, the lesson can stay focused on math skills.



Throughout the book, the positive benefits of inclusion are highlighted. These are done not only by the authors sharing the results of studies and their own experience, but also by uplifting comments of families and teachers about their experiences with inclusive education.

Effective Teaching Strategies for Successful Inclusion: A Focus on Down Syndrome is produced by The PREP Program, 1101 17th Street NW, Calgary, AB T2N 2E5. Phone: 403-282-5011, E-mail: office@prepprog.org
Web page: www.prepprog.org

Statement of Policy and Disclaimer

This newsletter reports items of interest relating to Down Syndrome and will provide a forum for others. The Down Syndrome Community does not promote or recommend any therapy, product or treatment. The contents of the newsletter are for informational purposes only.

Budget Cuts Affect People with Disabilities

A budget update from the ARC of Washington State is titled "Signed, Sealed and Bewildered" since it is still uncertain as to where all the budget cuts will fall. Governor Locke signed the 2002 supplemental operating budget, which removed an additional \$37 million dollars from the state budget including \$4.2 million for small homecare workers. Locke explained that the state could not afford the pay raise, no matter how slight. Elimination of the 25 cent per hour raise was made "while putting a high value on the service that homecare workers provide for disabled and elderly people." For families already struggling to find a respite provider that is willing to work for an already low wage, this will increase the difficulty.

Continue to advocate – we must be the voice for our loved ones. They should not be expected to do with less – it is up to us to secure quality of life for them, now and in the future.

Altogether, the revised state budget eliminates \$227 million in DSHS-administered funds during Fiscal Year 2003, which begins July 1, 2002.

Other changes on the chopping block include the elimination of the CAP Waiver Program. This waiver of family income enabled middle class families access to much-needed services

for their children with disabilities. Now if you have a child under 18 and are not low income as defined by federal rules (close to the poverty/welfare line), you may lose Medical coupons and MPCare (Medicaid Personal Care) for your child. This has been a lifeline for many families that struggle physically, emotionally and financially to care for their child in the home.

Continue to advocate – we must be the voice for our loved ones. They should not be expected to do with less – it is up to us to secure quality of life for them, now and in the future.

Call, e-mail or write Governor Locke and your Legislator – tell your concerns.

Additionally, Margaret-Lee Thompson is collecting letters about how the policy changes resulting from the 2002 Legislative budget are affecting your family. These shared stories will be part of a file for advocacy. Contact Margaret-Lee Thompson at 425-883-6721 or email at mlthompson@foxinternet.net.

***Call, email or write
Governor Locke and
your Legislator – tell
your concerns.***

A Special Fit

A Minnesota company has designed a special line of clothing for men with Down syndrome. The clothes are ideal for adults with Down syndrome who are short in stature. There are currently two styles of shirts and two styles of pants available. Additional men's and women's clothing are being developed.

Clothing is available online at www.specialfitonline.com or through:

Special Fit
18323 234th Circle
Hutchinson, MN 55350
320-587-8777
ddesens@hutchtel.net

Girl Scouts Partner with DSC

Girl Scout Troop 3165 from Buriem has partnered with the Down Syndrome Community for community service. The Scouts have assisted with the Holiday Party, the Sweetheart Dance, and the Des Moines area AT HOMES. The girls have helped set up, clean up, organize activities, and anything in between. For the AT HOMES they brainstormed crafts and other activities for the kids.

We are grateful for the help and assistance of the girls and their leaders and look forward to an ongoing relationship.

Thanks, Scouts!

Community Faces - "Say Daddy"

This article was originally published in the Parents Helping Parents June/July 2001 issue. Titled 'Say Daddy' it was written by our dear Down Syndrome Community member, Sean G. King.

It is said we all dream of the perfect child. Nonetheless, I challenge you to present a single person who can define "perfect child." As the father to a nearly two-year-old son with Down syndrome, I bristle every time someone mentions the concept of a perfect child.

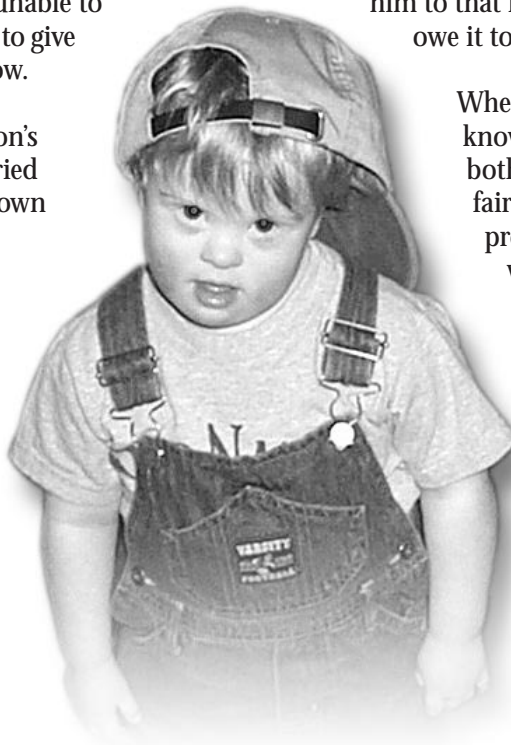
Martha Beck, an author and psychologist, wrote about perfection by describing how she felt while looking through baby magazines in a waiting room after learning her fetus had Down syndrome. "Practically every article featured pictures of newborn babies," she wrote, "and every baby was absolutely perfect: tiny perfect hands, strong perfect limbs, bright perfect eyes. The magazines didn't show any babies like the baby I was going to have." At one time, and perhaps still, Martha believed there were perfect children. Moreover – and this point is subtle but unmistakable in those two sentences – she believed her baby was imperfect, already a broken and flawed boy.

Like Martha, I knew my son, Ayman, had Down syndrome before he was born. And I did my share of mourning and grappling. In tears I called my mother and apologized for being unable to give her the grandson I had wanted to give her, as though I had failed somehow. My mind reeled with what people would think of me because of my son's disability. And I found myself worried about how I would cope with his Down syndrome for the rest of my life.

I don't like who I was in these memories. I was a self-centered man, concerned more with the splendid, perfect gift I would bring into the world, as though my baby were a shiny trophy, a fine sculpture, another impressive thing to show off. Then, poof! All dreams shattered, all hopes smashed. I took hold of myself and shook my figurative shoulders. Come on now. Get a grip. A life is coming, not a death. Not an ending, but a beginning – a chance to embrace, well, *chance*.

Looking at Ayman today, I wonder: Is he imperfect? Look at his exquisite face. Are his bright perfect eyes missing something? Do his perfectly crooked ears need straightening? Given the chance, would I take a hunk of spare clay and patch it onto his nose, destroying the perfect concave swoop of it? No way. Ayman's face does not need to be fixed. Ayman's face is not broken. When he smiles the faintest dimples appear in his cheeks, as if the sculptor took the heels of her palms and pressed them ever so lightly there.

True, his developmental delays do worry me. Some days I am filled with optimism, perhaps as I watch him work with a puzzle and get the pieces right, or as he stands for five seconds waving his outstretched arms in tight circles before landing on his cushy sacroiliac with a house-shaking thud. Some days, some rare days, I get sad and let my doubts and fears engulf me with pessimism. Usually this happens when I watch him interacting with peers. I see them romping all around him, bouncing and buoyant, and they seem so mature, so centered, so smart. And Ayman—God, if only there was something more I could *do* to get him to that level. I am his father. I feel like I owe it to him.



When I'm not in one of these funks, I know he is doing fine. Luckily for us both, Down syndrome seems to be a fairly easy disability to deal with. His progress is a steady upward curve, and while he so far hits the milestones, he consistently hits them a little later than his peers. But he gets there. He keeps getting to where the other kids were.

It's when I'm comparing him that I stumble. It's when I think about what he can't do, rather than what he has accomplished and the promise he possesses. I always snap out of my blues, usually when I realize that Ayman is having a blast. Look at him giggling and dancing. Watch him focus on a problem and work it

"Say Daddy," continued

through. Notice how he keeps trying to stand and yearns to walk, his hope impermeable. Ayman is having no problems with his development. The pain I feel is inside me and is generated by my competitive nature, my desire for perfection. It really has nothing to do with him.

Will Ayman be what I imagined a child of mine would be? Will he be bright, engaging, bold – an asset to his family and to society? Well, he just might. But then again, he might be more. He might be something I never thought of. I was selfish to dream of a perfect child, selfish to impose my hopes on a life loaded with unforeseeable possibility. It took Ayman to make this clear to me.

We are all gamblers and artists. We don't know what we will roll as we shake the dice of procreation. And what we end up with, if we are lucky enough to bring a soul into this world, is a life we can enrich and encourage, with the love and care an artist devotes to her work.

When Ayman first learned to say the word dog, he also applied it to me. I didn't mind. I had been called a dog by the worst kinds of characters. Besides, Ayman didn't mean "dog" as in dog, but "dog" as in Daddy. I can deal with that. No child is perfect.

In the end the goal is not to produce the perfect child according to some arbitrary ideal. Ideals of perfection are diverse and elusive. The goal is peak development of the individual, regardless of ability. The goal is to raise the most perfect Ayman or Chloe or Jonah you can raise. Given this premise, does it matter what you start with?



The King Family

Ways To Help The Down Syndrome Community

Albertsons Community Partner Cards

As part of the Albertsons Community Partners Program, the Down Syndrome Community is looking forward to receiving a rebate from Albertsons on every dollar we spend there each quarter. Just show your Community Partners card at the checkout stand and we will receive between 2% - 5% of our total purchases. Ask your friends & neighbors if they would like a card to help support Down Syndrome Community. Also, Albertsons has online grocery shopping where you may order at albertsons.com, give them your Community Partners card number and Down Syndrome Community will benefit. For cards call Sean King at 206-524-6124 or seanking@hotmail.com.

United Way

Contribute to the Down Syndrome Community through your employer's United Way/Combined Campaigns. It's easy to do, even though the Down Syndrome Community is not listed in their catalogues. Just write in "Down Syndrome Community" and the dollar amount you would like to contribute on the forms distributed to you during these campaigns. The campaigns will do the research through the State of Washington to identify us as a registered non-profit organization, and then direct the appropriate funds to us. Thank you for your financial support of the Down Syndrome Community.

A Note From The Editor

Down Syndrome Community continues to grow each year while being run entirely by volunteers – most of them family members. Each person that contributes by helping with events, making phone calls, our internet access, or even using their Albertson's card enables us to continue our support and advocacy for individuals with Down syndrome. Our heartfelt thank you to everyone that helped us during the year and made many things possible.

Contributions for this newsletter are always welcome. If you have ideas, news, or anything of interest to our membership please send it to: Linda Mason Kappes, 1720 NE 105th St. Seattle, WA 98125; or email at consult@cmc.net.

FLASH Discount Card

FLASH (Fun Leisure Access Savings and Health) replaces the discount/ID card previously issued to people with disabilities by the City of Seattle Human Services Department. Cardholders receive discounts on services and products, pet licenses, recreational facilities and much more. Applicants must be at least 18 years old and have a verifiable disability. For more information call 206-684-0500.



Membership Update

If you have made any changes in your address or membership information that needs to be updated in our database, please contact Gina Donahue at 425-825-9065 or ddanyssa@att.net. In addition to holding the Down Syndrome Community mailing list, the database also acts as a means of referrals for parents or families who want to reach other parents or families with similar situations.

Important note – if you change your e-mail address, please remember to contact Gina Donahue for updated changes.

Inspirational Message

This inspirational message was written by Erma Bombeck and provides a timely message for Mother's Day!

A Special Mother

Most women become mothers by accident, some by choice, a few by social pressure and a couple by habit. This year nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen? Somehow I visualize God hovering over the Earth, selecting his instruments for propagation with great care and deliberation. As he observes, he instructs his angels to make notes in a giant ledger.

"Armstrong, Beth, son. Patron saint, Matthew."

"Forest, Marjorie, daughter. Patron saint, Cecilia."

"Rutledge, Carrie, twins. Patron saint . . . give her Gerard – he's used to profanity."

Finally, he passes a name to an angel and smiles, "Give her a handicapped child."

The angel is curious. "Why this one God? She is so happy."

"Exactly," smiles God. "Could I give a handicapped child to a mother who does not know laughter? That would be cruel."

"But does she have patience?" asked the angel.

"I don't want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock of resentment wears off, she'll handle it."

"I watched her today. She has that sense of self and independence that are so rare and necessary in a mother. You see the child I'm going to give her has his own world.

She has to make him live in her world and that's not going to be easy."

"But Lord, I don't think she even believes in you."

God smiled. "No matter, I can fix that. This one is perfect.

She has just enough selfishness."

The angel gasps. "Selfishness? Is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, here is a woman that I will bless with a child that is less than perfect. She doesn't realize it yet but she is to be envied. She will never take for granted a spoken word. She will never consider a step ordinary. When her child says 'Momma' for the first time, she will be a witness to a miracle and know it. I will permit her to see clearly the things I see – ignorance, cruelty, prejudice – and allow her to rise above them. She will never be alone. I will be at their side every minute of every day of her life, because she is doing my work surely as she is here by my side."

"And what about her patron saint?" asks the angel, pen poised.

God smiles, "A mirror will suffice."



Down Syndrome Community Calendar

- May 10* Board Meeting 7PM Location TBA
- May 18* Annual Meeting/Potluck 5-8PM
Church of Nazarene, Seattle.
Info: ljmichael@cypressmail.com
- June 1* Deadline for newsletter submissions
- June 8* Board Strategic Planning Meeting
- July 3* Mariner's Night tickets available, flyer enclosed
- July/August* Annual Summer Picnic, Location TBA
- September 6-8* Camp Prime Time

LAUNCH Calendar

- May 16* Speaker Pat Oelwein on reading and math
for children with Down syndrome
- June 14* Mom's Luncheon and Swim
with Host JoAnne Thelin
South Seattle
- July 18* Adult Family Home Visit
- August 15* Update on Division of Developmental Disabilities
Speaker TBA. Highland Community Center
- September 15* Back to School BBQ Potluck. Location TBA

LAUNCH meets the third Thursday of every month. Unless stated otherwise, meetings are held at Highland Community Center in Bellevue. Babysitting is generally provided. For more information or registration contact JoAnne Thelin at 206-431-9777 or Lynn Chittenden 425-643-3768.



COMPUTER CONNECTIONS

Washington PAVE (Parents are Vital in Education) is a statewide parent training and information center that provides information about the Individuals with Disabilities Act (IDEA). For information contact www.washingtonpave.org or call 1-800-5-PARENT.

Fathers Network is a support and information network for fathers who have children with special needs. For more information access their website: www.fathersnetwork.org or call James May at 206-747-4004.

The *Washington Sibling Support Project* is dedicated to the interest of brothers and sisters of people with special needs. Call 206-527-5711 or check their website: www.cchmc.org/departmt/sibshop

The *ARC of Washington State* is an advocate of services and programs for people with developmental disabilities. Call 360-357-5596 or e-mail arc@earthlink.net
The ARC will also send a truck to your house for donated items (clothing, small household/sport/electrical) All donations are tax deductible. To schedule a pickup call 1-800-826-4310 or email arcdonate@earthlink.net.

Access Washington Resource Directory provides a directory of services for citizens of Washington State. It lists organizations for food, housing, counseling, education, employment, medical, disability. www.awrd.org



membership

Yes! I want to be a member of the Down Syndrome Community.

Your check helps defray the cost of publishing this newsletter and sponsoring social events. *Thank You!*

Enclosed is my check for: \$15.00 Other \$ _____

(Please make checks payable to *Down Syndrome Community*)

Renewal New Member

Name _____ Phone _____

Address _____

Name and birthdate of child with DS _____

I can not help financially, but please keep me on the mailing list.

Mailing Address:

**Down Syndrome Community
c/o Sean King, Treasurer
116 NE 59th
Seattle, WA 98105**