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

DSC President Receives National Award



Kirk Gillett, President of the Board for the Down Syndrome Community, has received the Secretary's Award for Volunteer Service from the Department of Transportation. Kirk and his wife, Ramona, traveled to Washington D.C. on November 14th for the presentation of the award by Transportation Secretary Mineta. Kirk was nominated for this award by his supervisor for the work he has done with the Down Syndrome Community. The DSC congratulates Kirk on receiving this well-deserved honor.

Kirk and Ramona are the parents of two boys, Spencer, age 8, and Blake, age 6. They became involved in the Down Syndrome Community while Spencer was still a baby. They were founding members of LAUNCH (Leadership, Advocacy, Understanding and Networking for a Community of Hope), a group of new parents with young children who reached out to each other for support and built the active network they are today.

Kirk and Ramona then became members of the DSC leadership and were elected as Board members when we became a non-profit organization in 1998. In fact, Kirk was our first Treasurer after we gained that status.

Ramona was on the committee for the DSC Conference in 1996 and suggested we host our first Buddy Walk in 1997. Ramona continued her involvement with the Buddy Walk committees and the Board for two more years with Kirk taking care of the kids at home while she attended meetings. But eventually Ramona's business took off and Kirk decided to take a more active role in the Buddy Walks as Ramona stepped down. The rest is, as they say, history. Kirk has played a major role in the success of the raffle for the last three years and was the co-coordinator and emcee of the Walk for the last two years.

It's nice to see the efforts of this dedicated man recognized nationally. But there has also been local recognition. The Everett Herald published an article about the award on November 12th and The Seattle Times, Snohomish County edition covered it on November 27th. Local news coverage is a great way to share information about our group and the work we do. Thanks, Kirk, for all you've done and continue to do to lead our organization. *— submitted by Linda Michael*

A Message From the DSC President *— by Kirk Gillett*

As I look back on the eight years that I have been involved in the Down Syndrome Community (DSC) I am continuously reminded of how blessed I am to be associated with such a wonderful group of people. As an organization we have come a long, long way from our beginnings. Do you ever wonder how the Down Syndrome Community got started? I am going to try and tell you. The reason why I say "try" is because the DSC roots go back to 1988-89 and I became a member in 1994, so the early years are very sketchy. I have picked the minds of our veteran members to help me explain how the DSC began.

In 1988-89 a small group of parents began meeting on a regular basis to support each other in raising their children with Down syndrome. The first meeting, organized by Amy Jahn and Vicki Loudon, drew parents from Federal Way to Woodinville. The group met in homes and shared stories of success and of heartache, just like we do today. The group quickly outgrew the homes so the Renton Good Neighbor Center offered their facility. These are the parents that paved the way for many of us that are raising young kids today. I personally want to say "THANK YOU" for fighting battles with the medical,

educational, and legislative communities to make it much better for us today. Yes, we still have battles, but they are not as bad because of the battles you fought and won years ago.

During the early years the parents discussed what the group's goals and objectives should be. One early focus was on conferences that would bring together professionals from various disciplines in the area of developmental disabilities. From 1990 to 1996, with the help of Pat Oelwein, a series of four conferences was held at the University of Washington

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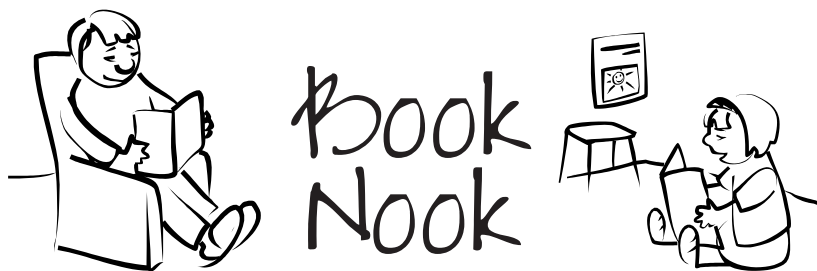
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What's green, spiky, and missing toes? It's Zaki, the iguana, and she's Moses' friend!

In school, a teacher gives Moses and the rest of his class a new assignment to write about a friend. This starts Moses thinking about all of his friends and what they share together. His friends include classmates like Manuel, who races with Moses on the playground, his teacher, Ms. Bird, and even his Mom and Dad. He also considers Kate, his babysitter, a close friend. Katie has an iguana named Zaki who is missing toes, making it hard for her to walk and climb. That's it! Moses, who uses a wheelchair, decides to write about Zaki because he and Zaki have a lot in common! They both have special needs.

More than just a story about friendship, **ALL KINDS OF FRIENDS, EVEN GREEN!** Looks at difference in a clever yet subtle way. With this beautifully photographed and engaging story, children discover that facing challenges can be a positive experience. The Afterword includes information about disabilities and additional background information about Moses (who has spina bifida and sacral agenesis) and Zaki - all of which can be used to lead a discussion about disability and difference with friends and students.



The author, Ellen B. Senisi, is a children's book author and photographer of more than 10 books, one of which is also about disabilities – the award winning **JUST KIDS** (Dutton, 1998).

Published by Woodbine House 1-800-843-7323 or www.woodbinehouse.com

DSC Board Recruiting New Members

The Down Syndrome Community Board of Directors is requesting nominations for the Board of Directors. Board terms are for three years, and Board members are asked to commit to board meetings every other month, an annual planning meeting, and to take a leadership role in planning DSC events, fund-raising and other activities that keep our organization going – and growing.

If you know of anyone who might be interested in serving on the Board, or if you are, please contact one of the Board members for additional information or join us at our next Board meeting on March 14th.

Nominations must be received in writing by the Executive Committee by April 1, 2003. Please submit all nominations directly to Kirk Gillett (gillett@prodigy.net), Lynn Chittenden (lynn_chittenden@msn.com), Linda Michael (ljmichael@cypressmail.com), or Sean King (seangking@hotmail.com).

This call for nominations is in accordance with the bylaws of the Down Syndrome Community and is officially posted by Linda Michael, Secretary.

A Message From the DSC President

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Experimental Education Unit. They also started a small newsletter that was called "The Powerline". The DSC received help from the ARC of King County for reproduction and mailing of the newsletter. By the second conference the mailing list had grown to more than 300 families all across the Northwest.

From 1991 to 1994 the group went through a lot of ups and downs. The core group of parents worked to keep the group together. The leadership invited speakers to come talk about various topics important to everyone from inclusive education programs to independent living after school. They also prepared information packets for distribution to area hospitals for new parents of a child with Down syndrome. This program took on new vigor in 1994 after we received a \$500 grant from the March of Dimes to fund the packets and to develop a DSC brochure to be included in the hospital packets. In addition to the packets, a small group of moms visited area hospitals and provided training to nurses on how to respond positively to parents who had just given birth to a child with Down syndrome. The major social event of the year was the annual Holiday Party with a visit from Santa and Mrs. Claus, a tradition that continues today.

From 1994 to 1996 a group of new parents formed a small group within the greater DSC to discuss their unique needs for support. This group quickly began to take on a life of its own and a core group, led by Lynn Chittenden, took the lead and decided they needed to be more formalized with goals and objectives for meeting the groups needs. Thus in 1997, L.A.U.N.C.H. (Leadership, Advocacy, Understanding, and Networking for a Community of Hope) was born. LAUNCH is an affiliate group within the DSC. They provide a monthly guest speaker series (open to everyone) on the third Thursday of each month at the Highland Community Center in Bellevue. They also have quarterly outings for families.

In 1996, Ramona Gillett read an article in the National Down Syndrome Society newsletter about the first Buddy Walk that was held in New York City. The NDSS wanted to establish a Buddy Walk in every major city across America. Ramona said, "We have to have a Buddy Walk in Seattle." Our first Buddy Walk was held in October 1997, and has grown to be our largest and only fundraising event with over 600 people participating in this year's 6th Annual Buddy Walk.

In 1998, the leadership decided to pursue non-profit status. We sought the advice of legal counsel who helped us write our Articles of Incorporation and Bylaws. The bylaws were adopted and our first Board of Directors was elected in May 1998. We then applied with the IRS to obtain our 501(c)(3) Non-Profit status, which we obtained in January 1999.

In 2001, the DSC received money in memory of Heidi Heier and the Board decided to establish a Memorial Lending Library in her honor. The money donated was used to purchase books, videos, tapes and other resource materials that our members can checkout and use at no cost. All memorials received are added to this library fund so the library can continue to grow.

The Board also began holding annual planning meetings to discuss and schedule our activities/events for the upcoming year. With one event scheduled each month throughout the year, this planning session has helped us have a very smooth year for the past two years. The Board is in the process of developing a 5-year Strategic Plan that will help us record and document the policies and procedures for the DSC.

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The Highland Community Center

You may have noticed that many of our events take place at the Highland Community Center in Bellevue. LAUNCH meetings have been held at this site every third Thursday of each month for the past several years. In February, DSC will host the Sweetheart Dance which is one of several events we sponsor throughout the year at the Highland Community Center.

These activities are in keeping with the Highland Community Center mission statement "to provide people who have disabilities with opportunities for recreation, socialization and learning so they can participate more successfully in the life of the community." In addition to providing space for our members, they serve individuals of all ages with more than 60 different disabling conditions with specialized recreation programs, after school events, social clubs, and field trips.

Their philosophy is to provide a variety of opportunities to insure that individuals with disabilities have recreational choices. They are committed to working with people with disabilities, their families and caregivers to make it possible for each person to participate in the least restrictive environment. They believe that individuals should have the choice of participating in recreation programs that offer the greatest opportunities for successful participation in both inclusionary and specialized recreation programs.

Highland Community Center, although well funded, still struggles to meet the needs of our community. Today, the biggest funding needs are daycamps and day programs that serve individuals with disabilities. The cost of these programs can range from two to three thousand dollars each. Today's climate of current cutbacks makes it more critical that people continue to support and advocate for this needed facility and resource.

For more information, or to provide support, contact Highland Community Center at 14224 Bel-Red Road, Bellevue, phone 425-452-7686.

**Thank you to everyone who contributed to the success of the
2002 Buddy Walk.**

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Guests, Entertainers, and Volunteers

Cheryl Chow, Guest Speaker
Kari Sellars, Guest Speaker
Rep. Al O'Brien, 1st District
Rep. Mike Cooper, 21st District
Rep. Aaron Reardon, 38th District
Rep. Toby Nixon, 45th District
Rep. Sharon Tomiko-Santos, 37th District
Rep. Fred Jarrett, 41st District
Rep. Frank Chopp, 43rd District
Senator Dino Rossi, 5th District
Clara Link, Photography
Lupita Cano, Artist
Bruce Savadow, photographer

Seattle Chinese Community Girls Drill Team
and Lion Dancers
Band — Less is More — David Boettcher, Perry
Delaney, John Typpi, Greg Bonus, Tim Moeller
Bruce Poliak — bagpipes
The Mariner Moose and Ashley
Boeing Klown Klub
Girl Scouts from Seattle Totem Council, Service Units
#030 and #035
Boy Scout Troop #419
Shariana Mundi of VSA arts of Washington
All the wonderful volunteers

And a special thanks to the Buddy Walk Committee for all their planning and hard work



Down Syndrome Community Featured in NDSS News

The Summer/Fall issue of the National Down Syndrome Society featured the following article in their 'Affiliate Spotlight' column:

Serving the diverse needs of more than 600 families in the greater Puget Sound region of Washington, the Down Syndrome Community offers something for everyone. New and experienced parents, family members, children and young adults can find their niche among the events and programs of this 14-year-old organization.

Popular programs for parents include guest speaker nights, open houses, new parent information packets, and a quarterly newsletter. The annual meeting has evolved from a business meeting to include an awards program that recognizes outstanding contributions of time and/or money. In addition, group members have an active social agenda including seasonal dances, holiday parties, picnics, and trips to Safeco Field to cheer on the Seattle Mariners.

The entire group gets together each October to make the group's largest advocacy event and fund-raiser, the Buddy Walk, a success. Now in its sixth year, the Down Syndrome Community Buddy Walk in downtown Seattle has attracted up to 600 walkers and major local media attention.

The Down Syndrome Community, which began as a small support group for parents, is now so vast and inclusive that an affiliate sub-group has evolved to continue meeting parent's basic needs. The sub-group called LAUNCH (Leadership, Advocacy, Understanding, and Networking for a Community of Hope) hosts guest speakers and playdates.

Kirk Gillett, president of the Down Syndrome Community, says members are pleased with the group's continued growth and success. The group should stay on track with the implementation of a new five-year strategic plan currently being developed. But, he explained, "All this does not happen without struggles. One of the biggest challenges we face is finding new volunteers to help with the many activities. We need new parents to conduct the new parents support group and to help organize a conference next summer."

More information about the Down Syndrome Community is online at www.downsyndromecommunity.org, and is also available by e-mailing Mr. Gillett at gillettk@prodigy.net.

A Note From The Editor

The 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.

Ways To Help The Down Syndrome Community

Albertsons Community Partner Cards

As part of the Albertsons Community Partners Program, The Down Syndrome Community receives 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 The Down Syndrome Community. Also, Albertsons has online grocery shopping where you may order at albertsons.com, give them your Community Partners card number and The 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.

Community Faces

Jim Cerjance, 45 years old and born with Down syndrome, has been employed at the Everett Outback Steakhouse for more than five years. During this time, Jim has enjoyed working various assignments with many managers and co-employees.



Due to illness in 2001, Jim was unable to work for several months. The Everett Outback Steakhouse provided Jim the needed inspiration to get well by assuring him that his job would be waiting for him when he recovered.

The Everett Outback Steakhouse is truly the difference between ordinary and extraordinary. Jim and his family are sincerely grateful for Joshua D. Coley, owner of the Everett Outback Steakhouse, and his crew for their gracious caring and truly 'walking the talk.'

Note: in addition to Jim, there are two other developmentally disabled adults that work at the Everett Outback Steakhouse.

– Submitted by Cheri and Stanley Clark

2003 Advocacy Day

Advocacy day will be held each Wednesday through April 16. Hosted by The ARC of Washington State, this is an opportunity to advocate and be heard by your Legislators. Held in Olympia, there is a morning briefing from 10AM until 11:30 that is focused on issues and updates of importance to the developmental disabilities community. There will be speakers on a number of different and timely topics. In the afternoon meet your Legislators and take a tour of the Capitol area to learn about the different buildings and functions. A typical day is from 8:30am - 4:30pm with transportation time. Arrangements can be made to meet at the Park and Ride lot or if you wish to drive yourself there are one time stipends available from the ARC. Call the ARC of Washington at 1-888-754-8798; grier@arcwa.org.

For information about carpools contact Cathy Murahashi at 425-643-4048, muracat@aol.com. For other information please contact Joanne O'Neill at 425-746-2178, jponeill45@hotmail.com.

Advocacy Day Calendar

February 5	Health Care
February 12	Family Issues
February 19	Employment
February 26	Provider Wages and Quality Assurance
March 5	Independent Living
March 12	Special Education and Birth-3
March 19	Transportation
March 26	Current Issues
April 2	Budget
April 9	Health Care
April 16	Session Wrap Up

"The moral test of government is how it treats those who are in the dawn of life - the children; those who are in the twilight of life - the aged; those who are in the shadows of life - the sick, the needy and the (disabled)."

– Former Vice President
Hubert Humphrey

From the Mercer Island Reporter

On Sunday, October 6, 3-year-old Jeffrey Pimentel took a walk with his buddy, the Mariner Moose.

The walk was the Down Syndrome Community's sixth annual Buddy Walk around Seattle Center grounds. It was one of the 125 around the country. Jeffrey's mom, Islander Charlene Pimentel, was a member of this year's Buddy Walk committee and arranged for the Moose to take part, after she had hired the Mariner mascot for Jeffrey's birthday.

October was Down Syndrome Awareness Month. The purpose of the walk is to promote acceptance and understanding of people with Down syndrome, a chromosomal condition that affects one in every 800 live births.

This year about 600 people walked in the event. "So word is getting out," Pimentel said.

The event featured guest speakers, a raffle drawing, dinner from the Outback Steakhouse, and entertainment. Donating to the event this year were the Pimentels, Mercer Island Chiropractic Clinic, Mercer Island Florist, the Mercer Island Police DARE unit and Studio 904.

Jeffrey goes to preschool at West Mercer Elementary four days a week. For the kids who need it, the school district will provide schooling, occupational and speech therapy beginning at age 3.

"We're lucky he has no medical problems," Pimentel said, "just delays in speech but he's a very animated little boy."

The Down Syndrome Community is a nonprofit organization that plans several events during the year for Puget Sound area families. It's a way for kids and families to have a network of support.

"It's nice to meet other kids and families and know that we're all going through the same things," Pimentel said. "The kids are just like everyone else."

For more information on the Down Syndrome Community, call 425-487-9648 or 206-241-0353 or visit www.downsyndromecommunity.org.

– Reprinted from the Mercer Island Reporter, November 11, 2002

A Message From the DSC President

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Due to the efforts of David Williams, who secured our domain name and also obtained a server at no cost to the DSC, our web site was up and running in early 2002. Please visit our web site at www.downsyndromecommunity.org. Any suggestions on how the web site can be improved can be forwarded to our Webmaster, David Williams at david_williams@msn.com.

During 2002 the Board of Directors voted to include "The UPSIDE" a Kitsap County Down syndrome support group as a DSC affiliate. The UPSIDE has existed in Kitsap County for years and consists of approximately 25 – 30 families and we are happy to have them a part of the DSC. The group is planning a special event for the greater DSC in May 2003, so watch your mailboxes for a flyer. Then hop on a ferry and join them for a fun filled day.

As you can see the Down Syndrome Community has come a long way from its beginnings back in 1989. I am even more excited about the future because as we grow and band together we can become a very strong voice to ensure a better future for our kids. Our next Board meeting is scheduled for Friday, March 14th, 2003 from 7 – 10 p.m. Anyone interested in attending is welcome. Please call me at 425-487-9648 or e-mail me at before the meeting so I can give you the specific location and agenda for the meeting.

– Kirk

Down Syndrome Community Calendar

- February 15* Sweetheart Dance/Pizza Party, 6pm-8:30pm
Highland Community Center, Bellevue
RSVP Sean King at 206-524-6124 or
seanking@hotmail.com
- March 14* Board Meeting, Location TBA
Contact Linda Michael at 206-241-0353
- March 22* Event TBA
- March 31* Deadline for Spring Newsletter submissions.
Contact Linda Mason Kappes at consult@cmc.net
- April 12* Bowling Night, Location TBA
- May 3* All-DSC Annual Meeting & Social, Location TBA
- May 9* Board Meeting, Location TBA
- June 6* Annual Planning Meeting DSC Board, Location TBA
- June 30* Deadline for Summer Newsletter submissions.
Contact Linda Mason Kappes at consult@cmc.net
- July* Mariners Night at Safeco Field
- July/August* AT HOMES, Locations TBA

LAUNCH Calendar

- February 20* IDEA Focus Group: Becoming an Effective Advocate
Highland Community Center, Bellevue
- March 8* Seminar on Positive Behavioral Support
Lindy O'Keefe, Speaker
10am-3pm, registration \$10 per person
- March 12* Advocacy Day 2003: Focus of Birth-3 and Education
State Capitol, Olympia
- April 17* Focus Groups at Highland Community Center
- April 26* Saturday Club for Kids – Bowling
- May 15* Stress Management and Relationships
- June 8* Tacoma Rainiers Baseball Game and
Father's Day Celebration, Tacoma
- June 19* LAUNCH Meeting – Focus Groups
- July 17* IDEA/Education Update at Highland Center
- July 26* Saturday Club for Kids – Adventure Island

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 at 425-643-3768.

2004 DSC Calendar Project

The volunteers working on the 2004 DSC calendar would like to thank each and every one of you who has shown interest in being photographed for the calendar. The applications and pictures we've received are terrific! It will be extremely difficult to narrow it down to the number of people we'll need for the calendar. The one common thread that each application contains is the pride and joy we share for our loved ones with Down syndrome. As many of the volunteers are mothers of infants and toddlers with Down syndrome, it is very empowering to see the accomplishments of so many of the people in the Down Syndrome Community.

Clara Link will photograph the selected candidates for the calendar. Clara is a professional photographer and a member of the Down Syndrome Community. Along with many other honors she's earned in her life, Clara was chosen as the photographer for the NDSC convention a few years ago. Her contribution speaks volumes about the message we hope the calendar sends.

The 2004 DSC Calendar will be available for purchase in the fall of 2003. The calendar is a fund-raising project with the profits benefiting the DSC. The success of this project will ensure our goal of creating a calendar annually. Information on how to obtain calendars will be forthcoming in future newsletter issues and on the DSC website.

The volunteers on the 2004 calendar include Linda Michael, Denise Medgard, Julia Wallace, Carla Snyder, Sandy Cadwell, Melody McMasters, Lynne Palmisano and Vicky Kerr.

– submitted by Denise Medgard

Membership Update

If you have made any changes in your address or membership information that needs to be updated in our database, please contact Linda Michael at 206-246-0353 or ljmichael@cypressmail.com. 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 Linda Michael with your updates.





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.
- To help defray costs, please send me the Down Syndrome Community newsletter electronically via email only.
Email address _____

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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.


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