



◆ Down Syndrome ◆ C O M M U N I T Y n e w s l e t t e r

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

Megan, Toys 'R' Us Superstar!

Some of you know me as Ms. Kitty, host of Megarama Day, a therapeutic riding program sponsored by the M bar C Ranch and the Forgotten Children's Fund. Others know me as aunt to the beautiful little red-haired girl named Megan Anne Schiedler. I created Megarama Day to celebrate my niece and all people with Down syndrome.



Megan is on the cover of the tenth edition of the Toys "R" Us Toy Guide for Differently Abled Kids. Two years ago we attended the NDSS convention in San Diego where someone told us Megan would make a great model for the Toys "R" Us catalog. Months later Toys "R" Us contacted Paula, Megan's mommy, and offered Megan her debut as a Toys "R" Us model. The Schiedlers flew to New York City in August of 2002 and had a blast: make-up, hair stylist, lights, camera, action and a smile that lights up a room. I was delighted when I found her picture inside the Seattle Times Toys "R" Us insert playing with a Polly Pocket dollhouse.



Last year Toys "R" Us again contacted Paula. They were looking for a little girl to grace the cover of their Guide for Differently Abled Kids. Also featured on the cover would be actor John Ritter along with his five-year-old daughter, Stella.

What an experience they had in Malibu with comedic John Ritter, his beautiful wife, Amy, and their darling daughter, Stella. Toys "R" Us chose John for the cover because his brother, Tom, has cerebral palsy and John

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2003 Buddy Walk A Success!

The 2003 Seattle Buddy Walk was a resounding success. This event has grown so much in the last seven years. Attendance has increased from about 250 in 1996 to over 700 people registered at this year's Walk.

Financially, the Walk is increasingly successful as well. Seattle Center again provided us with a wonderful, central location for this fun afternoon. Their sponsorship has been one of the anchors for this event. Outback Steakhouse of Lake Union supplied a wonderful meal at no cost. We're so thankful for the support of Michael Federico and his staff – and the tasty food they provided. Sponsorships and donations of raffle prizes, as well as other types of donations, come from many parts of the community. This community support shows that the Buddy Walk is successful in its primary goal – to raise awareness of Down syndrome in the community.

But the Buddy Walk is successful, too, because of the support of the members of the Down Syndrome Community. It is truly a "Community" event. From raffle ticket sales, to entertainers, to volunteers, speakers, and presenters, much of the Buddy Walk is a celebration of our community – and our talents.



For the first time this year, a member of our community provided some of the sign language interpretation. Nineteen year-old Aneeta Lonkar, daughter of DSC Board Member Rajeev Lonkar, signed during the stirring speech given by Clara Link. Aneeta has studied American Sign Language for several years and we thank her for sharing her skills with us. Our volunteer

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Letter From The Editor

Recently I heard a very touching song and interpreted the words as a message for our community. It follows:

The Gift I Came to Bring

*The time has come to take my place
To share the load and speak my peace.
To give the gift I came to bring
To choose a path and have a name.
Side by side with other souls
We'll keep the fire from burning low.
With a will and body strong
To build this road we walk along.*

Decades ago there was a group of parents who were determined to make a good life for their loved ones. It was a time when people with disabilities were rarely seen in our communities, hidden away in institutions, never expected to participate in a regular school, never given a chance at basic citizen rights. Faced with these challenges, this committed group of parents fought long and hard to make changes in society and the system. They carried the load of responsibility to make a difference so that today, our loved ones may benefit. It was an unplanned gift they gave to us.

It is our responsibility to continue advocacy on the path they 'trail blazed' for us. Despite gains made we still have a long way to go for inclusion and services. We must continue working "side by side with other souls, to keep the fire from burning low." Each of us can make a difference with a call to legislators, send letters or email about disability issues, volunteer or support your local disability groups (see 'Be Involved-Make a Difference' column for more suggestions). When you find an opportunity to advocate, take some time to help make a difference and continue to build this road we walk along.

Everlasting gratitude is expressed to those determined, caring people who decades ago, insisted on quality of life for their loved ones. Today it is our turn to share the load.

Thank you to Michael Pryor, a local Seattle songwriter and singer, for his inspirational words.

submitted by Linda Mason Kappes

DSC's Surprise Gift

On December 24th, an envelope stuffed with contributions arrived in the Down Syndrome Community's mailbox. Inside, a cover letter from The Capstan Fund's Douglas D. Atkins explained the unexpected gift. "Each Christmas for twenty years a group of men have gathered over lunch to sing Christmas carols in celebration of the season and their friendship. Each year we pass the hat for a local social service agency and surprise them with a donation. Bruce Milne, a longtime caroler, asked that we consider the Down Syndrome Community for this year's donation and we are pleased to do so. Thank you for your hard work and Merry Christmas."

We would like to extend our heartfelt gratitude to Bruce and all the gentlemen and their families for their generous contributions. It pleases us to be recognized and encouraged in this way, and gives us a powerful financial kick-start for the new year. Thank you!

DSC Yahoo Group

The Down Syndrome Community has an email announcement group through Yahoo Groups. Through this list information is shared about upcoming DSC events, as well as other events of interest, resources, and legislative news. You can join this group by sending a message to DownSyndromeCommunity-subscribe@yahoogroups.com.

If you have a Yahoo ID or Profile you can join on your own by going to www.yahogroups.com. Type Down Syndrome Community in the search window, then click on the link, and click on the Join this Group button. Also, if you have a Yahoo Profile, you can edit your membership in the group anytime - update your email address, change from individual emails to digest, or search the archives for past messages. Please consider setting up a Profile.



COMPUTER CONNECTIONS

Struggling Readers Intervention Program is a site featuring core reading programming, reading intervention for struggling

readers in middle school and high school. Direct instruction programs are also available for elementary through adult. The programs for struggling readers provide direct instruction in sound-symbol development, phonics, word recognition, reading fluency, plus more. www.strugglingreaders.com

The U.S. Office of Personnel Management recently launched a new site to provide information in Federal Employment for People with Disabilities. There is useful information for anyone seeking employment at www.opm.gov/disability

GPS locator for children is a personal locator to help locate your child within minutes. www.wherifywireless.com/prod_watches.htm

Video on Social Standards

Sometimes correct social behavior and expectations can be confusing to a child. Parents and teachers may have difficulty finding ways to communicate appropriate social behaviors to a child with special needs who already struggles with many other issues. However correct social behavior increases that child's chances of being successful at school and in the community. An award winning video 'Know the Code at School' presents social skills in a lively, story based format. Know the Code contains six segments: A Day at School, Charles Gets Teased, Dion Scores, Kristi's First Day, Shana and the Secret, and the Bully. Social skills are analyzed and made available for classroom discussion.

This video has companion educational materials forming a comprehensive program:

Know the Code at School behavior cards illustrate 50 social behaviors in five easy to follow steps. Each card shows a skill with a relevant photo, lists sequential steps, and suggests talking points.

Social Standards at School book focuses on 53 social skills, organized around a typical school day. Getting ready, classroom behavior, transitions, breaks, relationships and etiquette.

The book, cards and Know the Code video (also in DVD) are available from Attainment Company 1-800-327-4269 or online at www.AttainmentCompany.com.

Buddy Walk, continued

interpreter, Joani Bishop, of the Highline School District appreciated the help.

Guest speaker Clara Link from Tacoma is a long-time member of the DSC whose photography is featured in the DSC calendar, "Living it Up!" Clara's work was also displayed at the Walk, along with that of Lupita Cano, another long time member and talented artist.

Keynote Speaker Frank Chopp is the great-uncle of Griffin, from Vashon. Speaker of the House Chopp contrasted the future of Griffin and other children born now with that of his uncle with Down syndrome, whom he sadly never met.

Some of the entertainers came to us from DSC families, as well. Christina Levitz, one of the Mexican dancers in Bailadores de Bronce, is the sister of Jesus, a DSC member from the Burien area. Leading the Walk was Bruce Poliak on the bagpipes. Bruce is the uncle of Joey, another Burien area member.

Did you happen to notice the young adults who were greeting everyone and handing out programs as you entered? They were DSC members Marcie Mineard, Marcella Young, Brian Michael, Teddy Hatch, and Mary Beth Rispoli. It is great to have our young adults with Down syndrome lending a hand as volunteers at our events. Thank you!

Many of the volunteers at the face painting, fishpond, or registration tables were moms, dads, aunts, uncles, cousins, or friends of DSC members. Coordinating them all were Mary Jo Kelly, GERALYN DAVIS and Sheila Samples, aunts to Nicole. Without the extensive planning of these three ladies (and their spouses) it would be impossible to pull off the Buddy Walk.

So thank you to everyone who invited your friends, sold raffle tickets, solicited or donated raffle prizes, planned, or helped in any way with the 2003 Buddy Walk. Together we created a wonderfully successful, fun event.

submitted by Linda Michael

Thank you to everyone who contributed to the success of the 2003 Buddy Walk!

Presenting Sponsor



at Lake Union
Michael Federico, Proprietor

Co-Sponsor



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Billy McHales
Chuck & GERALYN DAVIS
Costco-Lynnwood, Aurora Village & Everett
Doug Milligan
Duke's Chowderhouse
El Gaucho Restaurant
Family Fun Center – Tukwila
Glen Acres Golf & Country Club
Harbour Towers Hotel & Suites
Hi-Line Bowling Lanes
Hotel Monaco
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Intiman Theatre
Jillian's
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KJR Sports Radio 950 AM
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Guests, Entertainers, and Volunteers

Frank Chopp – Speaker of the House of Representatives (WA), Keynote Speaker
Clara Link, Guest Speaker
Rep. Al O'Brien, 1st District
Rep. Rodney Tom – 48th District
Rep. Dave Upthegrove – 33rd District
Rep. Toby Nixon, 45th District
Rep. Fred Jarrett, 41st District
Lupita Cano, Artist
Bruce Savadow, photographer
Bailadores de Bronce – Mexican Dance Group
Rhys Thomas and his "Jugglemania" show
Bruce Poliak – bagpipes
Boeing Klown Klub
VSAarts of Washington
Pepper-d-Clown – Balloon Artist

All the wonderful volunteers!!!

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

Artist's Reception

The Issaquah Public Library was bursting with pride Sunday, October 26, 2003. The Down Syndrome Community hosted an Artist's Reception for Clara Link, the talented photographer whose work is showcased in the 2004 Down Syndrome Community Calendar – Living it Up!

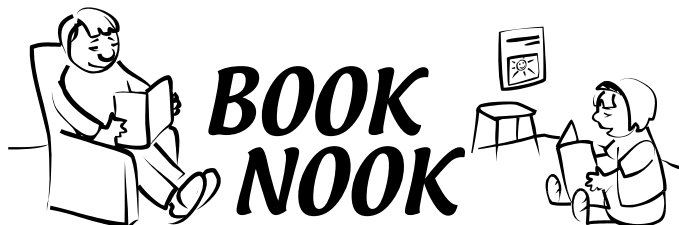
Many of those that attended were the individuals photographed by Clara for the 2004 calendar and their families. The calendar project was chronicled from conception to finished product, acknowledging the contributions of Clara, the committee, and all the others who helped to create the inaugural DSC calendar. As part of the program the DSC also presented each candidate photographed with a matted print of their photo from the calendar. Everyone approached the podium to accept his or her photo with the style and flair of any celebrity. The event was such a success; the DSC is hoping to make it an annual event.



The reception was the product of the community pooling their efforts and resources together to make it happen. The DSC would like to thank the Issaquah Public Library who not only allowed us to hold the event in their facility, but also provided space to exhibit information about Down syndrome throughout October, National Down Syndrome Awareness month. Starbuck's, QFC, and Safeway furnished food and drinks. Cadet Girl Scout Troop #785 from the Issaquah Service Unit provided much welcomed assistance with greeting and serving our guests.

For more on the calendar and order forms, visit our website at www.downsyndromecommunity.org

Transition to Middle School or High School is a difficult time for any child. Children with special needs may find additional challenges with inclusion, particularly if they are segregated from peers in a self-contained classroom. Two practical guides for constructively managing this problem are currently available:



Practical Strategies for Middle School Inclusion by Eileen Bowers provides clear directions for successful inclusion. She states "The inclusion model discussed in this book rests on a coteaching model where both the regular and special education teacher work side by side serving disabled and non-disabled children within the general curriculum in the regular classroom on a daily basis. A sample of chapter topics are: What Makes Inclusion Work?, Practical Strategies for CoTeaching Classroom, How Do I Organize All This?, Relationship Dynamics and more. In addition to academic strategies there are practical notes such as Locker Organization and Home to School Communication.

Practical Strategies for Including High School Students by June Stride provides practical strategies, tips and reproducibles to help make inclusion work. She explains the implications and legal aspects of preparing for and implementing inclusion for high school educators and administrators. A sample of chapter topics are: Modifications and Tips for a Productive Learning Environment, Evaluation Methods - Averting Frustration and Conflict and Promoting Academic Performance, Identification and Use of Supports to Inclusion - School, Parent, Peer and Community.

Both of these books are available from Attainment Company 1-800-327-4269 or www.AttainmentCompany.com
Attainment Company also has a free catalogue full of resources for the special needs population.

Odds 'n Ends

Membership Update

Please help us keep the information in the Membership Directory up to date. Current mailing or email addresses save time and money as we share notices of upcoming events or other information. To update contact Linda Michael at 206-241-0353 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/families who want to reach other parents/families with similar situations.

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.

Down Syndrome Community is online!

Check out our website at www.downsyndromecommunity.org

Also, if you would prefer to receive our newsletter and DSC flyers via email contact Linda Michael at ljmichael@cypressmail.com

Megan, continued

had raised millions of dollars for that cause. He was a strong and passionate supporter of improving the lives of children with special needs. He was an inspiration to all. At one point, John hugged Paula and said, "There is a heartstring between you and your daughter. It can get tugged, but it will never be broken."

Megan and family were scheduled to appear with John on Good Morning America in September. He was going to talk about his hit sitcom, "8 Simple Rules for Dating My Teenage Daughter," and about the Toy Guide. On the morning of September 11th, the Schiedler family purchased their airline tickets for New York City. Later that evening John Ritter passed away suddenly of an undetected heart problem, leaving us and the world stunned and heartbroken.

Although their hearts were heavy after losing their spokesperson, Toys "R" Us encouraged the Schiedlers to make the journey anyway. They gave Megan a \$500 shopping spree and a personal shopper at the Times Square Toys "R" Us. She also did a photo shoot playing a drum set that came out in a December Toys "R" Us newspaper insert. Santa Claus gave Megan those very drums for Christmas. I wonder how he knew.

We can all stop and take time out of our crazy schedules to see the possibilities of good things ahead. You just never know what's in store for you and your child around that corner. In this case it took Megan and her family coast to coast on an exciting adventure.

I remember a time shortly after Megan was born when I noticed a young male model in a Nordstrom catalog and showed the picture to my sister. We were intrigued. Later we met the model, Matt Hall, at the Seattle Buddy Walk. He became a friend and an inspiration to us. He gave us hope. Not just because he was a model, but because he was out there. He was showing up for life. I am proud of Megan and her family, but most of all my sister, Paula, for it takes a strong, brave, loving parent to raise a child with Down syndrome.

submitted by Louise Marian Avery

You can contact Louise at 206.461.5885 to learn more about Megarama Day or just to talk. For more on Megan, do an Internet search for Megan Anne Schiedler. You can see the Toys "R" Us cover online at www.toysrus.com/differentlyabledguide.

Down Syndrome Community Calendar

February 7	Sweetheart Dance & Pizza Party, 5:30 -8:30 Highland Community Center, Bellevue	April 30	DSC Board meeting open to all members. Location TBA - contact Linda Michael 206-241-0353
February 19	LAUNCH speaker Ellen McMille, Case Manager, A Guide to DDD Programs and Services 7-8:30PM Highland Community Center, Bellevue	April/May	Neighborhood Swim Party at three locations: North, East, South, to be announced
March 18	LAUNCH speaker Larry Jones, Attorney Creating Wills and Trusts 7-8:30PM Highland Community Center, Bellevue	May 8	Annual Meeting, location TBA
April 17	Focus on Safety Nets, discussion at Highland Community Center, Bellevue 7-8:30PM. For info contact Beth Angelo 425-814-1753	May 20	LAUNCH speaker Cindy Farricker on Nutrition for the Healthy Child at Highland Community Center, Bellevue 7-8:30PM
April 24	Saturday Club for Kids: Bowling and Burgers contact LAUNCH location TBA	June 17	Focus on Education presented by LAUNCH contact JoAnne Thelin 206-431-9777

LAUNCH (Leadership, Advocacy, Understanding and Networking for a Community of Hope) 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 206-431-9777, jrt414@yahoo.com or Lynn Chittenden 425-222-7770, lynn_chittenden@msn.com

Contribute to Down Syndrome Community

Contribute to the Down Syndrome Community through your employers 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.

M E M B E R S H I P

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 _____
- Please add me to the DSC Email announcement list on Yahoo.
Email address _____

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