



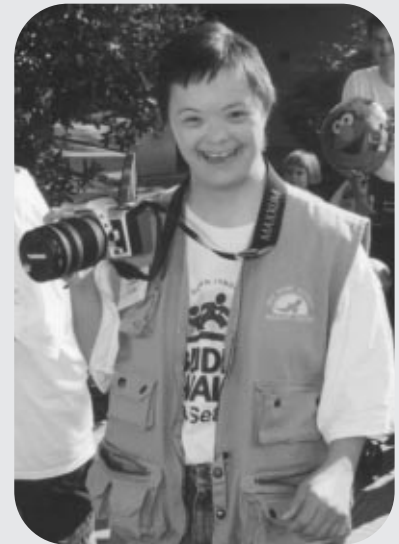
## ◆ Down Syndrome ◆ C O M M U N I T Y

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

### Buddy Walk

**It's Buddy Walk time again.** Grab your friends, neighbors, teachers, and any other buddies and come enjoy the fun at the 7th Annual Seattle Buddy Walk. Seattle Center has again sponsored us and provided the Fisher Pavilion Rooftop for our walk on **Sunday, October 5th from 1-4 PM.** Registration is from 1-1:30 with Mexican dancers "Bailadores de Bronce" creating a festive mood. At 1:30 we'll have the program with guest speakers including Clara Link, the photographer who took the photos for our 2004 DSC Calendar, Living It Up! By 2:15 we should be lining up with our Buddy Walk signs to circle Seattle Center and end up around the International Fountain. Then we'll head back to Fisher Pavilion Rooftop for a fantastic juggling show featuring Rhys Thomas of Jugglemania, who has performed all over the world. Check out his web site, [www.jugglemania.com](http://www.jugglemania.com) to build your anticipation. Next enjoy a delicious lunch provided by OUTBACK Steakhouse of Lake Union. Suggested donation is \$5/person or \$20/family with all proceeds benefiting the Down Syndrome Community.



There will be the ever-popular face painting, fish pond, arts and crafts booths, Boeving Klowns, plus a chance to buy raffle tickets and win great prizes. This year's prizes include an autographed Jamie Moyer Jersey, Alaska Airlines tickets, hotel and fine dining gift certificates, passes for Argosy Cruises, Intiman Theatre, golf, bowling, billiards, and so much more.

Thank you to OUTBACK Steakhouse of Lake Union, Seattle Center, Alaska Airlines and all the other sponsors and donors for their support.

Come join us for an afternoon of fun and celebrate Down Syndrome Awareness Month with all your buddies!

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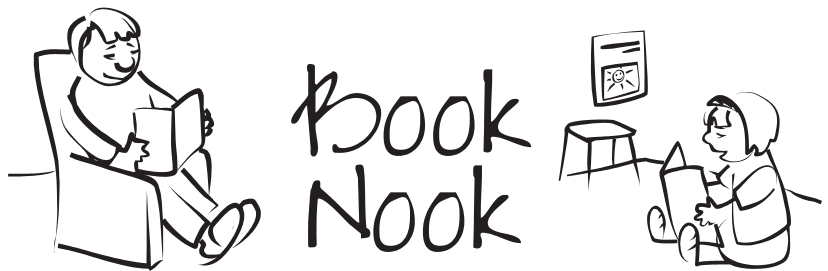
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A new book on communication by Libby Kumin has just been published. *Early Communication Skills For Children with Down Syndrome: A Guide For Parents and Professionals* is an updated expanded edition of the 1994 publication. It emphasizes how to maximize speech and language development of young children, from infants through age 5 or 6. It is intended for parents and those professionals working closely with the family including speech-language pathologists, early interventionist, and occupational therapist.

In *Early Communication Skills* the author incorporates the latest research on Down syndrome and communication development such as when to expect the acquisition of specific speech and language skills. New to this addition is information on apraxia (difficulty planning movements needed for speech) which has just recently become a more common diagnosis for children with Down syndrome.

There are chapters on: 1) augmentative and alternative communication and other high/low tech supplemental communication options, including a basic overview of how to use PECS (Picture Exchange Communication System); 2) articulation difficulties and how to improve intelligibility; and 3) literacy and how reading aids in the learning of language, speech, and auditory skills. New checklists on evaluating and treating speech problems, and numerous home activities designed to help children master each stage of communication development have also been added.

There is also additional information for parents on how to secure speech-language therapy and other accommodations for children with Down syndrome from the school system. Updates include legal information, reading lists and resources, and activities presented.

Published by: Woodbine House, 6510 Bells Mill Road, Bethesda, MD 20817;  
1-800-843-7323 [www.woodbinehouse.com](http://www.woodbinehouse.com)

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## 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, 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 [consult@cmc.net](mailto:consult@cmc.net)

## Sibling Slam Book Project

Of all age groups teens siblings are the most overlooked. There are some books aimed at younger sibs but nothing that specifically addresses the interests and concerns of 13-19 year old brothers and sisters.

Don Meyer, in collaboration with Woodbine House, intends to change this and develop a book by and for teenage sibs of kids with special needs; a book that gives a voice to teen sibs' concerns in a format that is teen-friendly.

They are looking for sibs, age 13-19 to participate in the Sibling Slam Book Project. If you would like more information contact

Don Meyer, Director

Sibling Support Project of the ARC of the United States  
6512 23rd Ave. NW #213, Seattle, WA 98117

Call: 206-297-6368

Email: donmeyer@siblingsupport.org

## Down Syndrome Community Online!

Check out our new website at

[www.downsyndromecommunity.org](http://www.downsyndromecommunity.org)



## 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.

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

## 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](mailto:DownSyndromeCommunity-subscribe@yahoogroups.com)

If you have a Yahoo ID or Profile you can join on your own by going to [www.yahoogroups.com](http://www.yahoogroups.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.

– Submitted by Linda Michael, membership

## A Great Gift Idea

*Wondering what to give that special teacher, therapist, friend, neighbor or relative for a holiday gift?*

The 2004 Down Syndrome Community Calendar is the perfect present that lasts all year! All proceeds benefit the Down Syndrome Community to help support our community events and outreach. Visit our web site at

[www.downsyndromecommunity.org](http://www.downsyndromecommunity.org)

for more information.

# Megarama Day!

A mighty good time was had at the M-Bar-C Ranch on Whidbey Island for the annual Megarama Day, hosted and sponsored by Louise Avery, her niece Megan, and the Concierge Guild. Families and friends of people with Down syndrome bounced along country roads for an adventurous hay ride, explored old western town buildings, rode friendly horses, and enjoyed a tasty BBQ lunch. Thanks to Louise and Megan for inviting members of the Down Syndrome Community to join in the fun.



**OUTBACK**<sup>®</sup>  
STEAKHOUSE

of Lake Union  
and the Down Syndrome Community  
present

NATIONAL DOWN SYNDROME SOCIETY  
  
**BUDDY  
WALK**  
of Seattle

**Sunday, October 5, 2003**

**1:00 - 4:00 p.m.**

Seattle Center  
Fisher Pavilion Rooftop

Co-sponsored by



**Celebrate Down Syndrome Awareness Month.  
Bring your friends and family.**

**Enjoy music, food, activities, clowns, raffle prizes, and more.  
Meal provided by Outback Steakhouse with proceeds to the  
Down Syndrome Community, serving the Puget Sound region.  
Suggested donation for meal - \$5 / person or \$20 /family**

For more information contact  
Kirk Gillett 425-487-9648

BuddyWalkSeattle2003@yahoo.com  
Linda Michael 206-241-0353

## A Year of Pride

### *Down syndrome calendar captures achievements*

By Sara Bader

Printed in the Issaquah Press on May 21, 2003

Reprint permission from Issaquah Press

As school graduations rapidly approach this time of year, many parents take stock of their children's accomplishments and future goals.

For Denise Medgard, however, every single day of every single month is a reminder of life's potential for her daughter, 5-year-old Lizi.

And that's why she decided to create a calendar for the Down Syndrome Community (DSC) — so everyone else could come to the same realization.

"This is the first Down syndrome calendar that I've ever heard of that actually captures people candidly doing activities," Medgard said. "It really speaks to the vision, which is people with Down syndrome out living their lives in the community, achieving goals and dreams and interests — just like everyone else."

She proposed the idea last summer after seeing similar calendars made in other states. As with Lizi, who attends Apollo Elementary, she knew local people with Down syndrome were leading very successful lives, and that could be translated beautifully into pictures.

Down syndrome is a congenital disorder caused by extra 21st-chromosome material in all or some cells, which results in a wide range of cognitive disabilities and other developmental delays.

All proceeds from the calendars will go to support the DSC, a nonprofit Puget Sound group that creates supportive, educational and fun activities for families living with Down syndrome.

Just as important, it will spread awareness and break down stereotypes, Medgard said.

The pictures feature all ages of people with Down syndrome working in professional jobs such as at the King County Courthouse, playing sports, taking courses at Bellevue Community College and just having fun.

But one of the most significant testaments to the calendar's message is behind the lens, not posing in front of it. Clara

Link, a 31-year-old woman from the Tacoma area with Down syndrome, has taken each photo, January through December. Link said she has known she wanted to be a photographer since she was little, and she now travels the country displaying and selling her pictures at seminars. Link also has written about and been featured in books about disabilities.

"I'm following my dream," Link said while snapping shot after shot, quickly adding, "I do weddings, too," when her mother, Yvone, neglects to mention it in her list of photography projects.

"She has been such a professional," Medgard said. "She's really talented."

At this shoot, Link is trying to get just the right picture of Lizi while she participates in a preschool gym class at Apollo. The tiny, pink-clad Lizi investigates Link's large lens that's pointing at her, then resumes spinning, jumping and more spinning as the children dance around before gathering for a game of duck-duck-goose.

Each of the 600 DSC members was asked to apply to be a calendar model, and Lizi was among those chosen out of about 60 submittals. Medgard picked this setting for the picture because it's one of Lizi's favorite parts of the day, she said.

In fact, Lizi is having so much fun she doesn't even run up to say hello to her mom when she walks in — something Medgard doesn't know whether to laugh or cry about.

Link joins right in, almost getting tagged herself as Lizi is dubbed the "goose" and dashes after a friend around a circle of students.

"She has so much fun with people, sometimes she forgets what she's doing," Yvone Link said with a laugh.

About six people from the DSC are working on producing the calendar. They want to have them ready for sale several weeks before October, when the organization holds its biggest yearly event, The Buddy Walk, in Seattle.

To promote the calendar, the group hopes local businesses will make order forms available for customers. Also, the Issaquah Library has agreed to host an exhibition of the photos sometime in the fall.

"The message is so positive, I hope everyone in the community finds some value in it," Medgard said.

## COMPUTER CONNECTIONS



It's 'back to school' time and some of the following sites may be helpful:

No Child Left Behind offers information on how legislation affects your child  
[www.nochildleftbehind.gov](http://www.nochildleftbehind.gov)

Bridges4Kids is dedicated to building partnerships between families, schools, and communities. Their website provides a wide variety of resources for those involved in the disability community. [www.bridges4kids.org/](http://www.bridges4kids.org/)

Center for Change in Transition Services features best-practices for the transition from high school to adult life for special education students as well as a wealth of resources and information. Check out the NEW Agency Connections. <http://depts.washington.edu/ccts/>

POST-ITT Transition Planning Resource is a free web-based resource designed to help students with disabilities make the transition from high school to college. It has comprehensive information about disability support services and activities designed to guide you through this process. [www.postitt.org](http://www.postitt.org)

The latest on school related legal issues at [www.wrightslaw.com](http://www.wrightslaw.com)



DSC President, Kirk Gillett, thanks Patrick O'Brien for new DSC logo design.

## Presenting the Down Syndrome Community 2004 Calendar

The Down Syndrome Community (DSC) is proud to present our 2004 calendar, "Living it Up!" Our vision has been to show adults and children with Down syndrome engaged in their lives, active in their communities, and living it up! This vision has been enhanced by the fact that our photographer, Clara Link, also has Down syndrome. We've created an opportunity for Clara to learn more about a craft she loves, gotten a glimpse into the lives of 14 individuals as they enjoy life, and hopefully, presented a well rounded view of the many and varied abilities and interests of these featured individuals.



(c) Clara Link

Response to the project has been extremely positive. Northwest Cable News recently aired a news segment about the calendar. Newspaper articles focusing on the calendar have been featured in the King County Journal and the Issaquah Press. In addition, an exhibit dedicated to the project will be featured at the Issaquah Public Library. The calendar committee is continuing to learn of additional interest throughout other media venues. This has been an exciting and effective way to raise awareness of people with Down syndrome.

We'd like to acknowledge the Production Illustration and Offset Printing program at Highline Community College. The printing and graphic design process was a rewarding experience for the students as they gained valuable hands-on experience on a large project. In addition, the instructors generously provided their time and expertise to advise and support us on technical and design aspects throughout the process. It was definitely a win-win situation. Highline Community College did a great job!

The 2004 calendar committee consists of mothers of children with Down syndrome who are also members of the DSC. Meetings were held often during the last year of the calendar's creation to track the progress of the project and strategize on upcoming tasks at hand. This gave the group an opportunity to foster friendships not only among each other, but between their children as well. It's been great.

The calendar makes a wonderful gift! When you order a calendar as a gift, we'll include a gift note indicating that the calendar is coming courtesy of you to your recipient. They are perfect for the holidays.

Calendars will also be available for purchase at all upcoming DSC events. In addition, an order form is available at [www.downsyndromecommunity.org](http://www.downsyndromecommunity.org). You may also call Linda Michael at (206) 241-0353 to order calendars. All proceeds from the sale of the calendar benefit the Down Syndrome Community.

2004 Calendar Committee for the Down Syndrome Community

## Down Syndrome Community Calendar

- October 5* Buddy Walk 1-4PM at Seattle Center Fisher Pavilion Rooftop
- October 16* LAUNCH Meeting/Focus groups. Highland Community Center, Bellevue
- October 25* Saturday Club for Kids, Jubilee Farms, Carnation  
Contact Lynn Chittenden 425-643-3768
- November 8* Harvest Party/Country Dance, Location TBA
- November 14* Board Meeting (open to all members) Location TBA.  
Contact Linda Michael 206-241-0353
- November 20* LAUNCH Meeting - Topic: Raising Fit and Healthy Kids. Highland Community Center, Bellevue
- December 1* Deadline for newsletter submissions. Contact Editor Linda Mason Kappes at [consult@cmc.net](mailto:consult@cmc.net)
- December 6* Annual Holiday Party. Location TBA
- December 18* LAUNCH Meeting/Focus groups. Highland Community Center, Bellevue
- January 9* Board Meeting (open to all members) Location TBA.  
Contact Linda Michael 206-241-0353
- January 15* LAUNCH/DSC Joint Meeting with guest speaker Highland Community Center, Bellevue
- January 24* LAUNCH Saturday Club for Kids. Contact JoAnne Thelin 206-431-9777
- February 7* Sweetheart Dance and Pizza Party. Location TBA
- February 19* LAUNCH Meeting/Focus groups. Highland Community Center, Bellevue

## LAUNCH News

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](mailto:jrt414@yahoo.com) or

Lynn Chittenden 425-643-3768,  
[lynn\\_chittenden@msn.com](mailto:lynn_chittenden@msn.com)

Focus groups (special interest groups) are currently forming to address the unique needs of LAUNCH members. These groups are invited to meet at the Highland Community Center on alternative months to our scheduled speakers and discuss issues of importance to those members. These "focus" groups will organize their own agendas and direction. Our popular Saturday Clubs will be offered quarterly again this year - we hope you can join us for these fun events!

Special thanks to the Highland Community Center for their continued support and donation of meeting space.

LAUNCH  
LAUNCH

## Ways to Help 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](http://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](mailto:seanking@hotmail.com).

### *United Way*

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 \_\_\_\_\_

Mailing Address:

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

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(425) 778-8095

**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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