

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

## Buddy Walk Wish List



Plans are underway for our 6th Seattle Buddy Walk, set for Sunday October 6th at Seattle Center's Fisher Terrace. The committee has been meeting and already has a great response. The Boeing Klowm Klub will be back to brighten the day, and the Girl Scouts are bringing lots of volunteers to help. But there's lots left to be done and the committee has put together a wish list of items/people that would help us pull together the best Buddy Walk yet. If you can help with any one of these items, or have other ideas for us, please contact one of our coordinators: Kirk Gillett at [gillettk@prodigy.net](mailto:gillettk@prodigy.net) or 425-487-9648, Linda Michael at [ljmichael@cypressmail.com](mailto:ljmichael@cypressmail.com) or 206-241-0353



## Wish List

**Volunteer Coordinator (s)** -- someone to recruit and organize the volunteers as well as supervise on the day of the Walk.

**Raffle Coordinator** -- someone to solicit the prizes, organize and prepare them for the drawing.

**Speaker** -- an adult self-advocate who can inspire us about their job and interests.

**Keynote Speaker** -- does anyone have a connection with a celebrity/well known personality who might like to speak at our Walk?

**Entertainment** -- we need entertainment from 1-1:30 during the registration and from 3-4:00 after the walk.

**Sponsors** -- we can never have too many. Send us the contact information, or if you're willing to contact them yourself - we can send you our sponsor packet to provide to them.

**Raffle Prizes** -- can you think of a favorite restaurant, hotel, etc. that might be willing to donate a gift certificate for a raffle prize? Send us their name.

**Fishing Booth Prizes** -- lots of small prizes to give out at the fishing tank.

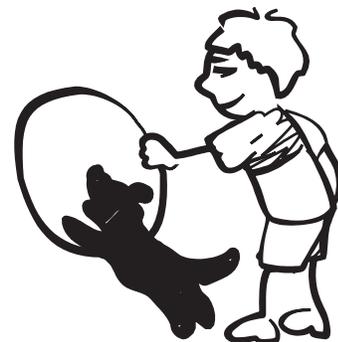
**Media contacts** -- do you know someone in the media who might be willing to help publicize the Walk?

**Face Painters** -- looking for a few more good volunteers since face painting is always a favorite part of the Walk.

**Other Activities** -- ideas and the know how and follow through to develop them!

**Printing/Signage** -- last year Sun Press Printing and Kinkos donated some of the printing and saved our non profit group lots of money. Do you know of anyone else who might be willing to help us so we don't wear out our welcome? We try to add a few more signs and banners each year so help with those would be especially appreciated.

**Creative Adults with DS** -- photographer Clara Link, and artist, Lupita Cano, displayed their work last year. We'd like to expand this part of the event, so please let us know of any other creative folks who'd like to share their talent with us.



## Board Members

**Kirk Gillett, President**  
425-487-9648  
gillettk@prodigy.net

**Lynn Chittenden, Vice President**  
425-643-3768  
lynn\_chittenden@msn.com

**Linda Michael, Secretary**  
206-241-0353  
ljmichael@cypressmail.com

**Sean King, Treasurer**  
206-524-6124  
seanking@hotmail.com

**Linda Mason Kappes, Newsletter**  
425-712-7060  
consult@cmc.net

**Nick Kappes**  
425-712-7060  
consult@cmc.net

**Rajeev Lonkar**  
206-362-5963  
rlonkar@msn.com

**Jodi Reimer,**  
*New Parent Contact & e-groups*  
253-839-2374  
reimeroo@aol.com

**Carla Snyder**  
425-432-2879  
jcsnyd@attbi.com

**Clarissa Suzawa**  
360-568-3093  
mcmkonthelake@juno.com

**David Williams**  
425-788-7442  
david\_williams@msn.com

**Sandy Cadwell**  
425-917-2236  
imjuskidn@juno.com

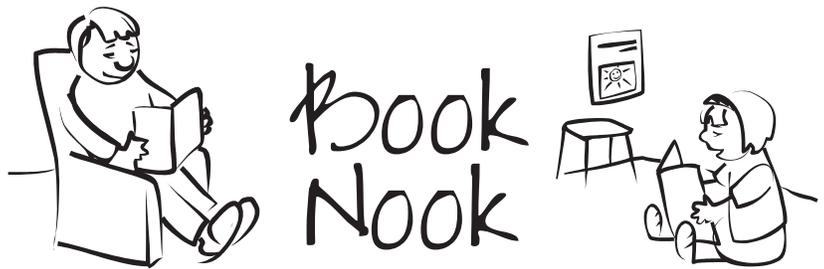
**Ann Mullis**  
206-842-9027  
amullis@telebyte.com

## LAUNCH

**Lynn Chittenden**  
425-643-3768  
lynn\_chittenden@msn.com

**JoAnne Thelin**  
206-431-9777  
jrt414@yahoo.com

**Beth Angelo**  
425-814-1753  
bangelo@juno.com



*Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals* is written for parents, health professionals, and teachers. This book is a practical and accessible guide to developing and understanding fine motor skills in children with Down syndrome from infancy to early adolescence. The author draws on her experience as a seasoned occupational therapist and parent to help children to prepare for and then master the hand

skills required for activities such as holding a pencil, cutting with scissors, or using a computer. Especially important is the book's sensitivity to the medical, physical, and psychological characteristics of Down syndrome and how they can affect motor development.

The first portion of the book begins by discussion about the building blocks of fine motor development: stability, bilateral coordination, and sensation and how they are the basis of successful hand coordination. Dozens of activities are provided complete with photographs and step-by-step instructions. Readers can choose among different categories of activities - self help, school, leisure and recreation - that are appropriate for different ages - babies to young teens. All activities are easily incorporated into daily routines and use everyday materials. Support and guidance is provided to help a child gradually build fine motor abilities and become more independent.

**Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals** by Maryanne Bruni, Bsc OT(C). Woodbine House 6510 Bells Mill Road, Bethesda, Maryland 20817. 1-800-843-7323.

### Down Syndrome Community online!

Check out our new website at [downsyndromecommunity.org](http://downsyndromecommunity.org)  
Also if you prefer to receive our newsletter and DSC flyers via email contact Linda Michael at [ljmichael@cypressmail.com](mailto:ljmichael@cypressmail.com)

#### 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.

## DSC Board Welcomes New Members

The Down Syndrome Community Board has grown this year to thirteen members. Voted in at our annual meeting was Sandy Cadwell of Renton. Sandy is the mom of Abigail who just turned two. Sandy is a great addition to the Board bringing lots of energy and jumping right in to help organize events in the coming year.

Anne Mullis has also just been voted in for a three year term with the Board through a special election. Anne and fellow Kitsap County resident Sharon Dommermuth approached the Board with a proposal to expand our organization by accepting their group, The UPSIDE - Kitsap County Down Syndrome Support Group, as an affiliate. The Board is proud to announce that this very dedicated group is now an affiliate of the DSC. Anne and Sharon have created an extensive packet of materials for new parents. This is just one of the projects that they've been instrumental in developing in their area. Anne is the parent of ten year old Jennifer. We welcome both of these new members to the Board and look forward to a productive year ahead.

## Language Usage Guide

Down vs. Down's. The Down syndrome Community agrees with the NDSS in their use of the preferred spelling, Down syndrome, rather than Down's syndrome. While Down syndrome is listed in many dictionaries with both popular spellings (with or without an apostrophe 's') the preferred usage in the United States is Down syndrome. This is because apostrophe 's' connotes ownership or possession. Down syndrome is named for the English physician John Langdon Down, who characterized, but did not have the condition. The AP Stylebook recommends using Down syndrome as well.

People with Down syndrome (or any disability) should always be referred to as people first. Instead of "the Down syndrome child" it should be "the child with Down syndrome". Also avoid "Down's child".

Down syndrome is a condition, not a disease.

People "have" Down syndrome, they don't "suffer from" it and are not "afflicted" by it.

It is clinically acceptable to say "mental retardation" but you may want to use the more socially acceptable, "cognitive disability" or "cognitive impairment".

In discussing education, the current trend is toward "inclusion", including the student in the regular classroom with appropriate modifications and support. That is different from "mainstreaming", which typically means putting the student in the regular classroom only for nonacademic subjects, while the rest of her time is spent in special ed.

For more information on reporting and writing about people with disabilities, visit <http://www.lsi.ukans.edu/rtcil/guidelin.htm>

## Down Syndrome Community Continues to Grow

UPSIDE, the Down Syndrome Support Group of Kitsap County and surrounding areas, would like to take this opportunity to thank the Seattle Down Syndrome Community for graciously adopting us! At the May Board of Directors meeting, we made a presentation describing our history, activities, current status, and future plans. We asked for sponsorship to become a chapter in your organization. This would provide you with growth, and us with the opportunity to raise funds as a 501(c)(3) to continue providing events and services to our members. We have approximately 30 families on our roster with wide geographical dispersion and family members with Down syndrome ranging in age from newborn to 40 plus. We look forward to our affiliation with and membership in the Down Syndrome Community, anticipating mutual benefits to all. At the June planning meeting, we volunteered to host the May 2003 activity for all. We hope that many of you can "cross the water" and join us. We'd like to get to know you better, so save the date - May 3, 2003.

And again, thank you.

Sincerely,

the Understanding potential  
Providing support  
Serving as advocates  
Improving opportunities  
Developing communities  
Ensuring success  
of Kitsap and surrounding areas



## Recognition

At the **2002 Annual Meeting and Potluck** recognition was given to some of the many volunteers who have built this organization. They have spent many hours behind the scenes organizing events and activities, creating newsletters, fund-raising, and all the other things that have kept our organization growing and vibrant. Please thank them when you see them for all they do for us.

### **Kirk Gillett** - *President*

Kirk has been on the Board for several years and served as Treasurer before being elected President in 2001. He has provided solid leadership ever since. That leadership has helped us to increase the number of activities and events, begin a Strategic planning process, add a Kitsap County affiliate, and much more. Kirk is also an integral part of the Buddy Walk Committee, last year serving as Raffle Coordinator. Thank you, Kirk, for your leadership, vision, and hard work.

### **Lynn Chittenden** - *Vice President*

In addition to being Vice President on the Executive Committee, Lynn leads LAUNCH (Leadership, Advocacy, Understanding and Networking for a Community of Hope). The LAUNCH program was once highlighted in Focus on the Family magazine, which gave the program worldwide recognition, and Lynn continues to receive emails from around the world. Lynn and her team provide monthly speakers at the Highland Center in Bellevue including childcare. Thank you Lynn for all you do.

### **Linda Michael** - *Secretary*

Linda has been involved in the DSC in various capacities since the early 1990's always on leadership and continues to serve as Secretary on the current Board of Directors. Linda has helped organize and put on conferences, she served as Treasurer and newsletter editor, she helped organize our first Buddy Walk nearly six years ago and continues to serve on the Buddy Walk Committee and is now serving on the DSC Executive Committee as Secretary. She is always there to lend a helping hand. Thank you, Linda, for everything you do.

### **Sean King** - *Treasurer*

Sean is serving his first term on the Board of Directors and immediately volunteered to be Treasurer. He has been the driving force behind the KBSG Dance and the Sweetheart Dance (and Pizza Feed). His organizational skills have contributed to the improved quality of the newsletter, and he creates a great flyer! Thanks Sean, for jumping right in from your first day on the Board.

### **Nick Kappes** - *Former President*

Nick has been involved in the DSC since its beginnings as a parent support group in the late 1980's. For years Nick and his wife, Linda, opened their home for us to hold Leadership meetings. Nick was instrumental in obtaining non-profit status for the DSC. He served as our first President once that process was complete. Thank you Nick for your service to all of us.

### **Linda Mason Kappes** - *Newsletter Editor*

Linda is recognized for her dedication and service to the DSC. Linda, along with Nick, has served the DSC since its beginnings. Linda has served as Editor for our quarterly newsletter since it was called 'Powerline'. Linda is making efforts to improve the quality of our newsletter, which was very evident in our latest issue. Thank you Linda for all your efforts.

### **Jodi Reimer**

Jodi is also serving in her first term on the Board of Directors in addition to her duties as the Parent-to-Parent Coordinator for the Arc of King County. Jodi has helped with revamping our brochure for the New Parent Packets, organized a Skiforall Adaptive Bike Event, coordinates and runs our Heidi Heier Memorial Lending Library, and is organizing Camp Prime Time for the DSC this year, in early September. Thank you Jodi for everything you do.

### **David Williams**

David has worked hard this year to get the Down Syndrome Community live on the Internet. David secured our domain on the Internet, facilitated the donation of a server that he set up, and subsequently designed our website at [www.downsyndromecommunity.org](http://www.downsyndromecommunity.org). David is currently serving his first term on the Board of Directors. Through his efforts we hold most of our Board meetings on the Microsoft campus. Thanks, David, for being our technical resource.

### **Carla Snyder**

Carla is serving her first term as a Director on the Board of Directors. She volunteered to organize 'Mariners Night' and arranged for the Down Syndrome Community to be up in lights on the diamond screen. Thank you Carla for taking the ball and running with it.

### **Rajeev Lonkar**

Rajeev is being recognized for his dedication and service to the DSC since the early 1990's. For years Rajeev and his wife Mangala organized our Camp Prime Time event and everyone that attended had a great weekend. He has been on the Board of Directors since the early 1990's and served as President for 200-2001. Thanks Rajeev for your service.

### **Clarissa Suzawa**

Clarissa is recognized for her dedication and service to the DSC while serving her first term on the Board of Directors and the Lead contact person/organizer for the Buddy Walk the last two years. Most of you come to the Buddy Walk and have a great time, but there are months of planning behind the scenes to make this a successful event. Thank you Clarissa for serving as the Buddy Walk Committee Chairperson and for organizing this year's Gym Night, too.

### **Gina Donahue**

Thank you Gina for your service on the DSC Board of Directors and for representing us at last year's National Down Syndrome Society conference. The information you brought back and shared has helped us become a better organization. Thank you for all your work in planning our Harvest Party and Gym Night and for taking care of the membership list during the time you served on the Board.

## Recognition continued

### **Beth Angelo**

Thank you Beth for the assistance you provide to the LAUNCH program, for developing the beautiful LAUNCH brochure, for setting up the "meet in the park" so our kids have a chance to play together. Beth organized a wonderful resource guide for the entire state of Washington and arranged for its continued production through Children's Hospital. What a wonderful resource for parents.

### **Dianne Mumma**

Dianne has been the organizer for our Holiday Party for the last several years. Thanks, Diane, for helping make that such a special event and for facilitating the use of your church for other events over the years.

### **JoAnne Thelin**

JoAnne and Lynn Chittenden are the heart of LAUNCH. Thank you, JoAnne, for sending out reminder postcards, and opening your home for LAUNCH planning meetings and everything else you do to keep LAUNCH going - and growing.

### **Ramona Gillett**

Ramona had a dream of doing a Buddy Walk in Seattle. Thank you for taking the initiative of turning your dream into a reality. Because of the groundwork you and your committee of three laid nearly six years ago the Buddy Walk has become the biggest and most exciting event we do all year. Ramona has served in leadership and also two years on the initial Board of Directors after we received our non-profit status.

### **Julie Hauf**

Thank you, Julie, for the assistance you give to the LAUNCH program, for helping set up childcare for the monthly LAUNCH meetings, and for your service on the LAUNCH steering committee.

### **Adrienne Monillas**

Thank you Adrienne, for your assistance in planning the Buddy Walk the past two years. Adrienne has successfully encouraged our legislators to come to the Walk.

### **Betsy McAlister**

Help with the Buddy Walk raffle and with the programs for kids like the fish tank, were a major success last year. Thank you for serving on the Buddy Walk Committee for the past two years.

### **Louise Avery**

Thank you Louise for always including DSC membership in the special day for your niece Megan, called "Megarama Day". We appreciate being included in this fun event.

### **Carrie Hickel**

Thank you for preparing the Discovery Grant package for the LAUNCH program this year. The funds you helped obtain are being used to cover the cost of childcare and printing/postage of the monthly flyers.

## 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](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 [seangking@hotmail.com](mailto:seangking@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

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](mailto:consult@cmc.net)

## Down Syndrome Logo Contest

The Down Syndrome Community needs a new Logo. Therefore, the Board of Directors is announcing a Logo Contest. The Logo will be used to identify our organization on all of our published materials including; official letterhead and envelopes, business cards, quarterly newsletters, web page, flyers, all publicity for the Buddy Walk, and other events we sponsor. This logo will help insure that our organization is recognized throughout the Puget Sound region and Western Washington.

Please submit your logo suggestions by September 1, 2002 to:  
Kirk Gillett -President  
10415 - 180th Street SE  
Snohomish, WA 98296-8125  
or by email at:  
GillettK@prodigy.net

A \$25 cash prize will be awarded to whoever designs the winning logo. Thanks again for your participation. Remember this is your organization so be creative, get the kids involved and have fun. We want our logo to be representative of our membership.

## 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 206-241-0353 or [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 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 for updated changes.

## Inspirational Message

*Let us be grateful to people who make us happy; they are the charming gardeners who make our souls blossom*

... Marcel Proust

*Happiness is the result of making a bouquet of those flowers within reach*

... Proverb

*The real things haven't changed. It is still best to be honest and truthful; to make the most of what we have; to be happy with simple pleasures; and have courage when things go wrong*

... Laura Ingalls Wilder

*Life is the first gift, love is the second and understanding the third*

... Marge Piercy

*A bird does not sing because it has an answer, it sings because it has a song*

... Proverb

## Political Advocacy

The future of our family members that have a disability depends on our involvement today. Resources that are available today exist because people advocated for them in the past. Continue to grow the seeds that were planted by those visionary individuals. Be involved and make a difference!

The Developmental Disabilities Council staff can give information at any time. They also provide weekly legislative updates during session. 1-800-634-1473 [www.wa.gov/ddc](http://www.wa.gov/ddc)

Washington Protection and Advocacy System staff answer legal questions. 1-800-562-2702

ARC of Washington website [www.arcwa.com](http://www.arcwa.com)

Parent Coalitions provide information on bills or local legislative efforts:

King County 425-883-6721

Pierce County 253-265-1961

Snohomish County 425-258-2459

1. Let Legislators know what your needs are and what you think.
2. Write a letter to senators at P.O. Box 40482 Olympia 98504; representatives at P.O. Box 40600, Olympia 98504; Governor Locke at Governor's Office Legislative Bldg. Olympia 98504.
3. Make a personal call to your legislators office.
4. Attend local meetings when your legislator meets in your home district.
5. Host local meetings and get to know your legislators.
6. Be in touch with county government officials-attend County Developmental Disabilities Board meetings, County Council meetings, etc.
7. Be involved in your local community through call in radio, letters to editor etc.
8. Washington State on the internet for daily reports [www.leg.wa.gov](http://www.leg.wa.gov)

If you can pick just one or two areas of interest and stay involved you can help make an enormous difference in your family's future.

## Ms. Sellars goes to Washington



PCC employee Kari Sellars spread the word about PCC while meeting with members of congress in Washington, D.C. Kari was part of a delegation to a national seminar on legislative issues affecting people with mental disabilities. Kari and her friends went to share their experiences and needs with their legislators face to face. Many decisions are made in Washington, D.C. that directly affect Kari's life and the lives of others with developmental disabilities.

The visit occurred as reauthorization of the Individuals with Disabilities Education Act (IDEA) and full funding of IDEA is before Congress. The delegation from Washington met with all 11 of our representatives. They now know that Kari works for PCC and that PCC is the kind of company that treasures her as a valued employee.

At the corporate office, Kari works as an Office Assistant. She does copying, assembles manuals, puts cancelled checks in numerical order, inputs data into the computer for cooking class programs, has made thousands of shelf tags, and runs the laminator. She types her schedule and does her timesheet through the computer.

Outside the office, Kari competes year-round in Special Olympics athletics. She regularly shares with her co-workers her latest medals in swimming, skiing, tennis and bowling.

Kari is among the first group of students in the nation to start and finish her public education under IDEA. Her academic and transition programs provided a basis for her successes in the community. Before IDEA, many children with Down syndrome were not accepted in public schools.

Washington Senator, Patty Murray, has been very involved in public education and supports full funding for IDEA. Kari and Senator Murray saw eye-to-eye on issues in education, health care, social security, employment, housing and transportation.

*-This article reprinted with permission from Puget Sound Consumer Cooperative Natural Markets June 2002 Sound Consumer*

## Down Syndrome Community Calendar

- September 1 Deadline for newsletter submissions
- September 6-8 Camp Prime Time. Contact Jodi Reimer
- September 13 Board Meeting 7PM
- September 15 Joint DSC/LAUNCH BBQ Potluck at Marymoor Park
- October 6 Buddy Walk at Seattle Center 1 PM
- November 8 Board Meeting 7PM
- November 9 Harvest Party/Country Dance TBA
- December 1 Deadline for newsletter submissions

## LAUNCH Calendar

- August 15 Update on Division of Developmental Disabilities Speaker TBA Highland Community Center
- September 15 Back to School BBQ Potluck. Marymoor Park

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



*The Arc of King County* has an online resource guide for children and adults with developmental disabilities living in King County. Community Connections is a work in progress. Changes and additions are made to this site on a regular basis, and some sections are still under construction.

The table of contents includes; education, health, legal, government, employment, recreation, support, services, disabilities, cultural, financial, housing, help desk, and index.

[www.arcofkingcounty.org/guide](http://www.arcofkingcounty.org/guide)

*The Arc of the United States* has an interactive site that allows individuals direct and easy access to Members of Congress and other federal agencies, information about important legislation, links to local media outlets; and information about candidates up for reelection. You can also sign up to receive the Arc's action alerts so that you can keep up to date on federal issues. [www.thearc.org](http://www.thearc.org)

*The Arc of Washington State* has a state legislature summary of the session for the week and will keep you updated on issues and alerts. The Legislative Hearings of Interest and The Bills of Interest information will keep you updated on the bills and work sessions in the legislature that may affect people with developmental disabilities.

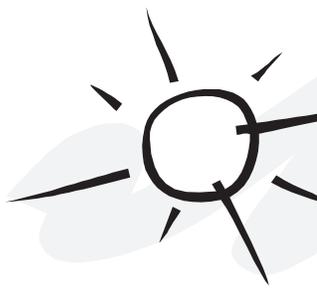
[www.arcwa.org](http://www.arcwa.org)

*The Washington State Division of Developmental Disabilities* is the official website for DDD.

[www1.dshs.wa.gov/ddd/index.shtml](http://www1.dshs.wa.gov/ddd/index.shtml)

*King County Division of Developmental Disabilities* has information about birth to three programs, employment, and community access.

[www.metrokc.gov/dchs/ddd/](http://www.metrokc.gov/dchs/ddd/)



# 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 \_\_\_\_\_

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