

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

Sweetheart Dance and Pizza Feed

The Down Syndrome Community hosted the Sweetheart Dance and Pizza Feed on February 16th this year at the Highland Center in Bellevue. This year's event featured music and lights from Foremost DJ and pizza from Godfather's. At the crafts table kids made better-late-than-never Valentines for their families and friends, while people of all ages danced to a wide variety of tunes. Dances for kids included the limbo and a Hula Hoop number, but contemporary pop, country and hits from the 50's through today's Top 40 are what made the evening really fly. The Down Syndrome Community received over 130 RSVPs for the dance, making it the biggest turnout yet for the annual event, and requiring thirty pizzas to feed the hungry partiers. Girl Scout Troop 3165 of Burien, veterans of the event, helped everything run smoothly. Thanks to all of you who donated dollars to cover the cost of the pizza, and a special thanks to the adults who stayed behind afterward to close up shop. Let's do it all again next year!



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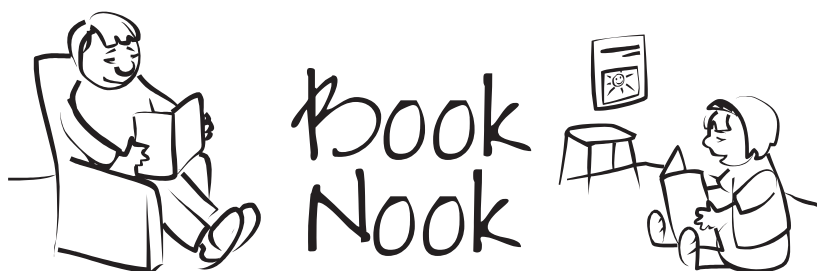
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THE DOWN SYNDROME NUTRITION HANDBOOK is the first book about nutrition education for professionals and families of children, teens, and adults with Down syndrome. It covers nutrition and weight management as well as the specific nutrition-related medical concerns people with Down syndrome may encounter.

This book is divided into four sections: Building Healthy Attitudes; Nutrition-Related Concerns for People with Down Syndrome; Teaching Healthy Choices to Encourage Healthy Lifestyles; and Learning Activities, each with strategies to promote communication, choice making, and participation. It is filled with practical opportunities to expose, teach, and practice key nutrition concepts that lead to making choices to live a healthy lifestyle.

This handbook is the culmination of the author's thirteen years as a Registered Licensed Dietitian working with children, teens, and adults with Down syndrome, as well as raising her own child with Down syndrome, now a teenage boy. Grounded in science and practical experience, offering workable solutions, and showing a profound respect for people with Down syndrome, THE DOWN SYNDROME NUTRITION HANDBOOK will appeal to parents, grandparents, dietitians, nutritionists, doctors, and anyone with an interest in the well being of people with Down syndrome.

THE DOWN SYNDROME NUTRITION HANDBOOK by Joan E. Guthrie Medlen, R.D., L.D. is published by Woodbine House. 1-800-843-7323
www.woodbinehouse.com

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.

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.

Sibling Support Project

The Sibling Support Project is the only national project in the United States dedicated to the concerns of brothers and sisters of people with special needs. They specialize in providing lively, family-friendly, and highly rated workshops on sibling issues to audiences of parents, service providers, university staff and students, and siblings of all ages.

Sibling Support Project has conducted workshops in all 50 states plus several other countries and helped establish over 200 replications in eight countries. Their books for families include Sibshops, Views from Our Shoes, Living with a Brother or Sister with Special Needs, and Uncommon Fathers.

They will present for agencies, conferences, or training events. These presentations will show how parents and providers can decrease sibling concerns and increase their opportunities, how to create 'sibling friendly' services, and even how to start your own Sibshop.

If you would like to learn more about seminars, keynotes or workshops contact:

Don Meyer, Director

Sibling Support Project of the ARC of the United States
6512 23rd Ave. NW #213, Seattle, WA 98117
206-297-6368 • donmeyer@siblingsupport.org

Down Syndrome Community Online!

Check out our new website at
downsyndromecommunity.org

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



Work Program for Special Needs

The Work Adjustment Program has been offered in the Edmonds School District for over 25 years as a means to teach general job readiness skills to special needs students. The program uses simulated tasks to approximate work tasks as well as contracted work from area businesses. This combination offers the students a unique opportunity



Andy Kappes is among the many students learning job skills at Work Adjustment.

to experience real world job activities, and when contract work is available, students may receive some pay for their participation on that work. The goal of the program is that our students develop a skill level that will provide them future success as employed workers in the community.

One business that has had a major impact on students is Holland America Line, Inc. in Seattle. The work Adjustment Program has contracted with HAL for over 20 years. Their support for our program has been outstanding. Through contracts with the Documentation Department and the Sales and Service Department, our students have learned about real work and it's value in the community. The HAL staff has been great in their willingness to provide meaningful work for our students. Sadly, with recent cutbacks, their need for our services for the Documentation Department has decreased. Hopefully, when the economy improves and the world settles down, our services will again be needed.

Another client that has been of great support to our program is Fish & Webster, also of Seattle, which designs fine stationary and note cards. The owner, Charlotte Graham has been a wonderful supporter for our students work experience. We have been working with Charlotte for about 3 years.

Without the support of the businesses in the community our students would not have opportunity to do real-world work. The variety of jobs done, the deadlines and the pay they receive help to prepare our students for the future. We thank our community supporters.

— Submitted by Mary Ogle, Work Adjustment Supervisor

Kids With Down Syndrome Learn Language Beyond Adolescence

Children with Down syndrome can face many challenges - health problems, hearing impairments, and learning disabilities, including those affecting language development. While modern advances in medicine have improved the health of children with this disability, a concern remains about the development of communication skills among these children.

Countering the claim among researchers that language learning in children with Down syndrome ends during the teen-age years, a new study from the University of Wisconsin-Madison suggests that individuals with Down syndrome can benefit from language intervention programs during adolescence.

Down syndrome is a developmental disability resulting from an extra copy of chromosome 21, and it affects about 5,000 newborns in the United States every year. A century ago, most children with this disability reached the age of only 9; today, they live well beyond their 50s.

Most children begin learning language skills such as grammar and speaking at rapid rates early in their lives. Children with Down syndrome, however, typically experience delays in language development, learning more slowly and at varying rates.

"There is a fanning out of skills in individuals that isn't seen in normally developing children," explains Robin Chapman, the study's primary investigator and a professor emeritus of communication disorders at UW-Madison's Waisman Center, a facility dedicated to advancing the understanding of developmental disabilities. For example, vocabulary learning may progress much more rapidly than the learning of sentence structure, she says.

Though all these skills continue to improve throughout childhood, Chapman says that some researchers have claimed that the skills begin to plateau as a child with Down syndrome reaches adolescence. As a result of this claim, she notes, educational opportunities for teenagers with this disability generally shift away from language learning.

Chapman's study, on the other hand, shows that certain language skills continue to improve well beyond the teenage years, suggesting that adolescents with Down syndrome should continue programs for language learning.

For the last six years, Chapman and her colleagues have charted the trajectory of learning skills and memory abilities in 31 individuals with Down syndrome who were ages 5-20 at the study's start. Through comprehension tests and storytelling

tasks, they measured each person's ability to understand complex grammar (language comprehension) and his or her ability to speak it (language expression).

While Chapman found that some language skills may stop developing as these children reach late adolescence, she also found that language expression skills continue to improve well into young adulthood - and that their development depends on the development of language comprehension skills, which do tend to plateau.

The longitudinal pattern of language learning in individuals with Down syndrome, says Chapman, shows that language comprehension skills quickly develop during childhood, but that development slows down as the child reaches the teenage years. Language expression skills run a different course. "The biggest gap in language learning occurs between language comprehension and expression," she says "but, unlike the other set, expression skills continue to improve throughout adolescence.

Chapman found, however, that the continued development of language expression depends on at least maintaining comprehension skills.

"The rate of change in expressive learning skills, she says, "is predicted by the rate of change in language comprehension skills." For example, if an adolescent acquires the ability to understand complex grammar more slowly, he will also acquire the ability to speak that grammar more slowly.

These findings, says Chapman, point to the importance of continuing language intervention during the teenage years: "The study's findings suggest that there should continue to be language work in both comprehension and expression throughout teenage and young adult years."

Furthermore, Chapman suggests that, because of the gap in the development of the two skill set, language instruction should alternate its emphasis between them.

"Kids with Down syndrome can accomplish a lot," Chapman says. "Think of Chris Burke who starred in the television show, 'Life Goes On.' We need to maximize the opportunities so they can accomplish even more."

The study was funded by the National Institutes of Health and the National Down Syndrome Society.

The findings are published in the October 2002 issue of the Journal of Speech, Language and Hearing Research.

Albertsons Community Partners Program Contributions Increase

Due to the growing number of members and friends who are using their Albertsons Community Partners Card when they shop at Albertsons, charitable contributions from the Idaho-based grocery store chain continue to increase. 2002 contributions increased by 35% over 2001, with quarterly distributions also hitting new highs every quarter. In 2002, Albertsons donated \$1547.44 to the Down Syndrome Community through this unique charitable giving program. Thank you, Albertsons, for continuing this outstanding program, and thanks to all the members and friends of the Down Syndrome Community for remembering to present their cards when they purchase groceries.

How the Program Works

Just contact Sean King (or 206-524-6124) to obtain a card. When you shop at Albertsons – any Albertsons in the country – simply present the card during checkout, and the checker will scan it. Here's the good part – no money comes out of your pocket. The quarterly earned contribution from Albertsons is a percentage of the cumulative amount of all the groceries purchased in the Down Syndrome Community's name. There is an upper limit to the quarterly contribution, but to date we have never come near that limit. So, please, continue shopping at Albertsons, keep using your Community Partners card, and ask everyone you know if they would consider participating, too.

Clinical Trial for Down Syndrome

A large, US-based, clinical trial of an investigational drug is currently underway and is recruiting young adults (18-35 years old) with Down syndrome to participate. The drug being studied is currently approved for the treatment of mild to moderate dementia of the Alzheimer's type and is being studied in the Down syndrome population for potential improvement in attention, language, orientation, memory and other areas. This study will involve 160 young adults and take place in 20 clinical centers nationwide. If you know of someone who might be interested in the study, please contact one of the centers below for more information

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 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.

about this clinical trial. The evaluations and medication in this study are provided to participants at no cost.

**University of Washington &
VA Puget Sound Health Care System
206-277-4682 or 1-800-329-8387 ext.6468**

**This clinical trial information is distributed as a public service by Down Syndrome Community with the understanding that DSC does not endorse or represent any medical, professional, or investigational services. Individuals are strongly encouraged to speak with their physicians regarding any questions they might have regarding the clinical trial.*

Megarama
Day!

Join Miss Kitty and the Ranch Crew on Saturday, July 19th from 9:00am to whenever on Whidbey Island! Amble through an old western town, ride a horse, listen to banjo music, and feast on a delicious BBQ. For a map and to RSVP, contact Miss Kitty at weezer@attbi.com or 206-285-6128.

COMPUTER CONNECTIONS



The sibling support project of the ARC of the US is pleased to announce SibNet and SibKids. SibNet and SibKids are the internet's only listserve for and about brothers and sisters of people with special health, developmental, and emotional needs.

Both SibKids (for younger sibs) and SibNet (for older sibs) allow brothers and sisters to connect with their peers from around the world. Both listserve have members in the US, Canada, Australia, England, Japan and elsewhere. SibNet (started in 1996) and SibKids (started in 1997) are remarkably warm, thoughtful, and informative communities where young and adult brothers and sisters can share information and discuss issues of common interest.

Anyone who has email can subscribe to SibKids and SibNet. For a no-cost subscription and to learn more, please visit the Sibling Support Project Web Page at www.thearc.org/siblingsupport/.

Miracle League Baseball in Monroe

The Miracle League is open to kids of all ages and disabilities. This is the fourth season and is sponsored by the Monroe Rotary Club and Boys and Girls Club. The season lasts for 6 weeks (1 game per week on Saturdays). Most games last for an hour and everyone hits, fields, and scores. Registration fee is \$20 which covers the cost of membership to the Boys and Girls Club, insurance, hats, shirts, and trophies. The registration fee can be waived upon request. To register contact Collette Reams at 360-794-8015 or email at collette.reams@ve

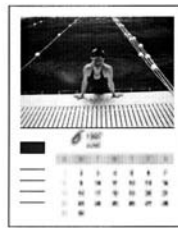
Snohomish County Volunteer Search and Rescue Project Lifesaver

The tendency to wander is prevalent among people that are suffering from Alzheimer's disease and other forms of dementia. People with Down syndrome, Autism, Prader-Willi or traumatic brain injury also exhibit this tendency. Reasoning, judgment, the ability to communicate are all affected by these conditions.

Project Lifesaver is designed to provide a safety net for the most vulnerable citizens in our community. Each Project Lifesaver client is provided a one-ounce electronic bracelet that emits a unique radio signal 24 hours a day. When a client wanders, a call to 911 by the caregiver triggers a rapid response by a trained team within the Snohomish County Volunteer Search and Rescue. Under the direction of the Sheriff's Office, a search is started to locate that clients unique radio signal as soon as possible.

Currently this program is only available for Snohomish County residents. If you have a loved one or know of an acquaintance or care provider that could benefit from involvement in Project Lifesaver, please contact:

Snohomish County Sheriff's Office
M/S 606 3000 Rockefeller, Everett, WA 98201
425-388-3825 Information Line • 425-388-3082 Volunteer Director
www.co.snohomish.wa.us/sheriff



2004 DOWN SYNDROME COMMUNITY CALENDAR

A production of the Down Syndrome Community with photographs by Clara Link
The perfect gift for family, friends, and neighbors
Available for shipping fall of 2003

Pre-Order Form
Mail completed order form along with a check or money order made payable to Down Syndrome Community to: DSC Calendar, 12931-168th Ave. S.E., Renton, WA 98059

Name: _____

Mailing Address: _____

Quantity: _____ @ \$10.00 ea. Sub Total: \$ _____

Shipping & Handling: @ \$1.50 ea. \$ _____

Grand Total: \$ _____

FEATURING LOCAL TALENT!!

Down Syndrome Community Calendar

- April 25* Board Meeting, 7PM Location TBA
- May 3* All DSC Annual Meeting and Potluck.
5pm - 8pm, First Church of the Nazarene
4401 2nd Avenue North, Seattle
RSVP to ljmichael@cypressmail.com
- June 6* Annual Planning Meeting DSC Board.
Location TBA
- June 31* Deadline for Summer newsletter submissions.
Contact Linda Mason Kappes at consult@cmc.net
- July* Mariners Night at Safeco Field
- July/Aug* AT HOMES locations TBA

LAUNCH Calendar

- April 26* Saturday Club for Kids - Bowling
- May 15* Stress Management and Relationships
- June 8* Tacoma Rainiers Baseball Game/Fathers 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

Events and Information

May 9 at 10AM Special Education 101 for Parents and Community Members. Learn about Seattle's new IEP Forms, Special Education Procedure Manual, and other special education related topics. Presented by Colleen Shea Stump at John Stanford Center, 2445 Third Ave. S, room 2750. Pre-registration required. RSVP to Sue Carroll at 206-252-0055

May 17 at 10AM-2PM Meet the Vendors. An opportunity to hear from employment agencies that serve individuals with developmental disabilities. Mercer View Community Center, 8236 SE 24th St., Mercer Island. To register contact Joanne O'Neill at 206-364-4645 ex.159

June 7 at 8AM-5PM Washington State Father's Network Statewide Conference. Seattle Central Community College. For more information call 425-747-4004 or www.fathersnetwork.org

LAUNCH News

LAUNCH is proud to be embarking on our 7th year. You'll notice our 2003 calendar has a new look. 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 to 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.

Educational Resources

The Special Education Technology Committee (SETC) has 3 primary components: 1) a lending library of hardware and software materials that districts use to evaluate long-term benefits for specific children (three week loan period), 2) training and technical assistance to school districts and parents, 3) technology planning for specific children. They are available to do consultations with your child's team to assist in deciding what technology might best help your child succeed in school. This would include hardware items (adaptive keyboards, switches etc.), software programs (Co-Writer, Kidspiration) and/or Augmentative Communication devices (talking word processors etc.). The only caveat is that someone from the school district must be the one to contact them (not a parent). The service is free and does not include a written assessment, but does look at long-term goals.

SETC Special Education Technology Center, Ellensburg 509-963-3350
SETC west side Tacoma 253-752-4276



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 _____

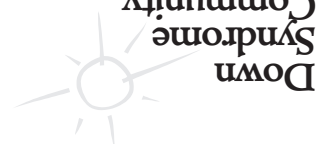
- I can not help financially, but please keep me on the mailing list.
- To help defray costs, please send me the Down Syndrome Community newsletter electronically via email only.
Email address _____

Mailing Address:
Down Syndrome Community
c/o Sean King, Treasurer
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Seattle, WA 98105



Design and Layout
by Pacific Art Press, Inc.
(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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