

STEPPING UP

July 2012 Issue 19

PUBLISHED BY THE NORTHWEST DOWN SYNDROME ASSOCIATION

CELEBRATING EVERY PERSON WITH A DISABILITY INCLUDING DOWN SYNDROME

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One little girl, one big difference

By Joni DeRouchie

Pamela Dye was anxious as she navigated the halls of the state capitol in Salem on her way to meet with Oregon State Representative Lew Frederick this past March. All the parents at the capitol that day felt the gravity of being face-to-face with lawmakers whose decisions and attitudes directly affect their children's future. Although Pamela was armed with literature and DVDs, she still wasn't sure what to say to Representative Frederick. After all, how do you tell a stranger all about your family's hopes and dreams in just a few minutes?

As it turns out, Pamela really didn't have to say anything.

Unlike the grown-ups, Pamela's daughter, six year old Jasmine, was unencumbered by ceremony and bounded into Mr. Frederick's office as though he'd just been waiting there all day for her arrival. Like anyone else who meets Jasmine, Mr. Frederick was immediately enchanted by her contagious charm. They chatted for a few minutes and posed for photos. By the time they left, Jasmine had a new friend and ally and had left a much stronger impression on Mr. Frederick than any pamphlet could.

Please see One Little Girl on page 3

Celebration: "Grow the Good"

By Angela Jarvis-Holland

As we launch into summer here at the NWDSA, we are celebrating some newfound capacity for our organization. Just in time for our board retreat in early June, we learned that we are the recipients of a grant from the Campbell Group's Grow the Good (GTG) initiative. The Campbell Group Portland office is a long-time sponsor and supporter of the NWDSA, and has a long history of supporting the local community and encouraging participation among employees. GTG is a company-wide annual giving and volunteer campaign that continues the spirit of giving on which the company was founded. Each Campbell Group office is given a designated amount of seed money to use to improve the lives of people in their respective communities. Employees determine how the funds are distributed.

Last year Grow the Good helped us to purchase a DVD duplicator that allowed us to press the *We All Belong* DVD that continues to do good work in many settings educating about inclusion and the right to belong.

NWDSA Program Director Angela Frome and I met with the GTG staff this spring to discuss our programs and priorities. It was a very interesting experience to be in front of a panel of Campbell Group staff members who wanted to know about our work.



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Stepping Up is published quarterly by the Northwest Down Syndrome Association (NWDSA), a non-profit organization managed by a board of volunteers.

To be added to our mailing list please visit www.nwdsa.org or send your mailing info to the address above. There is no subscription fee, but if you would like to make a donation, you may send a tax deductible contribution to the NWDSA at the address listed above or use PayPal on our website.

Readers are welcome to submit letters and articles to the address above or e-mail abraithwaite@nwdsa.org. Please include your name, address, phone number and e-mail. All submissions will be reviewed and edited for content and style.

The NWDSA Mission:

Create and nurture a loving and inclusive community celebrating every person with a disability including Down syndrome.

The NWDSA will accomplish this mission by empowering and supporting families and individuals who have been touched by Down syndrome. We will work to increase education, promote public understanding and acceptance, and toward full inclusion of individuals with Down syndrome in our community.

Opinions published in Stepping Up are not necessarily those of the NWDSA



Dear families and friends of the NWDSA

By Steve Holland, NWDSA President

The NWDSA Board of Directors held its annual retreat the weekend of June 6-8. Retreats are a very important element of non-profit management, as they serve the dual purpose of bringing all Board members together for a few days of intensive work and reflection, and providing the opportunity to focus on key initiatives for the coming year.

The theme of this year's retreat was organizational sustainability - in terms of staffing, community partnerships, volunteer support and funding. Board member Becky Adelmann served as our facilitator for the weekend, and was instrumental in helping us prioritize and capture the important elements of our work, and kept us on track so we could get the most out of the time invested. We also welcomed our newest Board member, Michelle Wallace of Vancouver. Michelle is the mom of Lupita, 7, and Sophia, 5, and has experience working with the Arc of Southwest Washington and the Clark County Parent Coalition. She has volunteered with the NWDSA on projects ranging from Buddy Walk to the Holiday Bizarre, from All Born (In) to the Summer Social, and we are very pleased that she has agreed to serve as Board Secretary.

The Board spent a day and a half on a full agenda of important items including an update to our strategic plan; reviewing and planning around our key projects; reviewing our technology needs; and a look at our financial current status. We evaluated our capacity to carry out our work, and identified the need to



engage new staff members, including a position dedicated to development and fundraising, and if possible, a half-time New Parent Outreach and community support position. We also discussed how to best utilize volunteers and how to make the most out of our relationships with professionals.

We reviewed the various collaborative projects we are doing with other groups in our community and region, and how to leverage these relationships to best serve our families and people with disabilities. We also discussed an exciting emerging partnership with Community Vision, focused on empowering young adults in developing employment and independent living opportunities.

We celebrated the successes of the past year, including record attendance and fund raising at our Buddy Walk, as well as record attendance at April's All Born (In) conference. The Kindergarten Cohort program just celebrated its third group of graduates! We also recognized the expanded level of volunteer support with over 1,000 hours of volunteer time over the last 12 months, and we are greatly encouraged by our ongoing build-out of partnerships with various advocacy, professional, educational, and other disability focused groups.

One little girl

Continued from page 1

That's the power of personal, one-on-one contact and the reason why advocacy events like this one are so important.

The NWDSA organized this event to facilitate conversations with Oregon lawmakers, but there was plenty of opportunity for public discourse as well. The All Born (In) banners, featuring beautiful images and quotes of inclusion, stood proudly in the atrium of the capitol building. Passers-by stopped to admire the banners, take literature and learn more about the NWDSA and the All Born (In) movement.

While parents visited the offices of legislators, NWDSA Executive Director Angela Jarvis-Holland spent time with Ben Cannon and Duke Shepard, advisors to the office of Governor Kitzhaber. She took them on a tour of the banners and spoke about the families in the images. She told them about the challenges parents face helping their children get the education they deserve, and how important it is for groups such as the NWDSA to have strong and productive relationships with those in office.

Parents, teachers, advocates, and lawmakers can get so embroiled in the day-to-day struggle of budget constraints and legal interpretations that they lose sight of their goals. It is vitally important to occasionally step back and take a moment to think about the children at the heart of all the fuss and remember that everyone wants to same thing—an excellent education for all children.

The next time Representative Frederick is in a position to stand up for the civil rights of school-age children with disabilities, he will hopefully remember that little girl who lit up his office with her smile, and realize that nothing should stand between her and the education to which she is lawfully entitled.





Above, L to R: Quinn Jarvis-Holland; Ben Cannon, Education Advisor to the Governor; Abigail Geoffroy; Angela Jarvis-Holland; Duke Shepard, Policy Advisor to the Governor













Creativity by Jane

I have no name
Until you name me.
I have no form
Until you shape me.
I don't exist
Until you make me,
I am creativity.
I am waiting deep inside you
Touch my spark
And let me light you,
Give me life
And I'll revive you
I am creativity.

Grow the Good

Continued from page 1

We dug deeply and reflected on our most essential need, to build some capacity to make the NWDSA more sustainable as an organization. After two in-depth conversations, GTG agreed to partner with us to fund a staff position dedicated to fundraising and sustainability. The NWDSA's new Director of Development will work on traditional fundraising and grant writing, with an additional focus on volunteer management and community asset development.

We used time at the Board Retreat to develop a job description, and we are delighted to report that after an interview process, Amy Geoffroy has accepted this position and is excited to get to work with us to secure the resources we need for our critical work. Amy has been the volunteer Chair of the Development Board for a few months now, and comes to us with a sound professional resume in non-profit development work. She is also the mom of two daughters, Emily and Abigail, and a board member of Down Syndrome Pregnancy, an organization that supports expectant mothers who have received a prenatal Down syndrome diagnosis. As Director of Development, Amy will be able to concentrate her considerable fundraising and grant writing skills on our needs.

It is together in community that we can truly "grow the good" and we will make very good use of this investment in the NWDSA. We greatly appreciated getting to know more of the amazing employees at The Campbell Group, and look forward to continuing to expand our connections with this great group of people!

Message from the Board

Continued from page 2

And most importantly we affirmed our dedication to our core work of supporting families and individuals with drop-in hours at our Resourcefulness Center, ongoing phone support, new parent out-reach, and the Reciprocal Learning Community, as well as continued work on disability and inclusion advocacy, genetic testing issues, creating new best practices media, and broadening the distribution of the *We All Belong* DVD. We also are proud of the improved and expanded nwdsa.org website and the ongoing focus on expanding our use of technology where appropriate.

In closing, I want to take a few lines to recognize the fabulous staff from the Multnomah Early Childhood Program (MECP) for all the progressive work they have done to include children and prepare them for kindergarten. The contract for Early Intervention was awarded by the State or Oregon to the David Douglas School District and we are glad to report that almost all of the staff from MECP will be moving over. We are sad to not be in the same building any longer but will continue to build on the good work we have created together and the strong relationships we have. Change is an inevitable part of the systems we rely on and we are looking forward to creating some new partnerships and opportunities for our families.

We are also very grateful for our home base in MESD, where we are supported in our work in many positive ways. Having access to the training spaces, light airy offices and volunteer and play space adds a lot of capacity to our work.

Take care and enjoy the summer!

Steven Holland

Reciprocal Learning Community continues to grow

By Janine Paschal

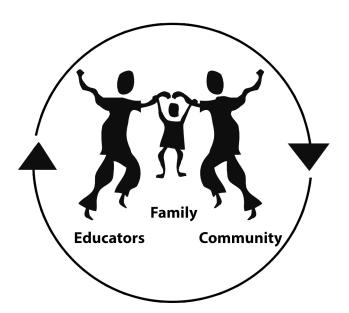
It's been a year since I started helping coordinate the Reciprocal Learning Community (RLC) -- a really satisfying year. We've heard professionals share their knowledge and experience, heard family members tell about their own lives and offer tips and tricks, and shared family stories and successes. Event topics included early childhood literacy, feeding and nutrition, and sensory issues. RLC attendees walked away with an enormous amount of useful information and valuable connections, not to mention some cool door prizes. Attendance nearly doubled from that first session last June to our latest session!

The RLC provides a fabulous opportunity to get to know people and strengthen our community. Even though my own daughter is fast approaching her seventh birthday, I find that in every session I learn new strategies that will help me support her and advocate for her. I also find that there are many things that I wish I had known when she was in the birth to 5 age range, which is our target audience for the RLC.

We are excited about the next RLC session, "Let's Move! Gross Motor Development in the Early Years". Physical therapists Peggy Donovan and Annette Sabater will share information about motor skill acquisition in an interactive session with lots of show and tell. Check www.nwdsa.org for more information and to register. Let's keep that attendance growing!

Also coming up are some fundraiser events to help us keep the RLC running. From July 29 through August 2, tear or cut out the flyer on the back of this newsletter (or download and print the flyer from the NWDSA website) and take it with you to California Pizza Kitchen in Clackamas. California Pizza Kitchen will donate 20% of your bill to the NWDSA. Share the information with family, friends, neighbors, teachers, anyone you think would be interested! There is no limit to the number of people who can participate, they just need to show their server the flyer. Flyers will also be available at the Resourcefulness Center and at the Summer Social. Watch for more information and dates for events at Burgerville.

We'd love to have your help with future RLC events. Specific needs include help with childcare, event planning, and logistical help on the day of the RLC. Please contact jpaschal@nwdsa.org if you or someone you know is interested in becoming involved.





Next RLC Session: "Let's Move! Gross Motor Development in the Early Years"

Saturday, September 7th Resurrection Lutheran Church 1700 NE 132nd Ave., Portland OR visit www.nwdsa.org for more info











The 2013 All Born (In) Conference

The 8th Annual ABI Conference was a great success, with over 400 parents, educators, artists and inclusion advocates in attendance.

Thank you to all the volunteers, sponsors and presenters who made the day possible, as well as each participant who spent the day with us. It is incredible to see the passion and skills of such a large group come together to make change that will help all children, all schools and all communities.

Please visit the Resources Page at www.allbornin.org to find all of the downloadable resources from conference sessions and presenters.

Feedback from conference attendees:

"Enjoyed the opportunity to be "real" with families and educators."

"It is what real community organizing looks like!"

"Look at how many MORE people are learning how to write successful IEPs this year. Education is so important!"

"Just the shot in the arm we needed! Thank you Angela, NWDSA and all the strong leaders and advocates who help shine the light...So grateful."





Build a Buddy Walk team and win an iPad!

By Angela Frome

The 15th annual Portland and Southwest Washington Buddy Walk Festival is coming up on September 28, and we're working hard to make it the best walk yet! I am excited to announce that Michelle Wallace will be joining me as committee co-chair this year. Michelle is the mother of Lupita and Sophia and the NWDSA's newest board member. We are both excited to work with all of you to create a great day for our community!

And now we need your help! We have a goal this year of bringing a half-time staff member onto our team to support New Parent Outreach and community building, and Buddy Walk funds will go to support this position, as well as to Family Socials, the Reciprocal Learning Community and Open Arms Playgroups.

How can you help?

- Register today! Buddy Walk registration is live online. Visit the NWDSA
 website (www.nwdsa.org) and click on the "Buddy Walk" tab at the
 top to find the link to register your family for the walk!
- Build a great team! New this year, we will be offering some fabulous prizes for the top money raising teams. All teams who raise \$3,500 or more by Wednesday, September 25th at NOON will receive an Apple iPad. Stay tuned at www.nwdsa.org for more prize opportunities!
- Help find Corporate Sponsors! Do you have a connection with a local company, or a favorite local business that might like to get involved with the Buddy Walk? We have a prepared sponsorship pack that we can send you to share with potential donors.
- Build a Silent Auction basket or help solicit raffle prizes! We have some great raffle and auction prizes piling up at the Resourcefulness Center, but we can always use more! If you know of a business or individual who might want to donate products, services or a night or two in their vacation home, please let us know!
- Join the Buddy Walk Committee! Want to roll up your sleeves and get a little more involved this year? Please consider joining us at the Buddy Walk Committee meetings this summer and really be a part of things! We have meetings scheduled for Wednesday, July 17th and Wednesday, August 14th from 6-8 pm.

As usual, Buddy Walk is shaping up to be a great family festival. We will be welcoming some fabulous entertainers this year, including walk veterans Tony Starlight, the Cloud City Garrison and the Portland Fire Department and more, as well as some new faces. JJ Jump and Parties Inc. will be back to organize the bounce house and kids' carnival games, complete with prizes donated by JJ Jump. Hooperville USA will be back with lots of hula hoop action. Portland Prime and Lee Farms will provide food for everyone and we'll also have Dreyer's ice cream, and special treats from Kidz With Ice.

For more information or to RSVP for the meetings, please call Angela Frome at (503) 238-0522 or e-mail afrome@nwdsa.org.





Buddy Walk fun over the years









Families enjoying the World Down Syndrome Day celebration at Portland Prime, March 21st 2013.





Kindergarten Inclusion Cohort: Sign Up Now!

By Alicia Delashmutt

Summertime and the livin' is easy! Your bouncing baby is now an active 4-year old and your summer will probably be full of visits to the local fountain, pool and park. It's hard to believe that the transition from early childhood education to kindergarten could be just around the corner!

Sign up now and join us this fall for the Kindergarten Inclusion Cohort (KIC).

Designed for parents whose child will be starting kindergarten in September of 2014, the Kindergarten Inclusion Cohort program is a series of interactive and best practices-driven trainings designed to help parents prepare and advocate for inclusive kindergarten placements for their children. Over the course of six monthly sessions, families will gain valuable information to assist them in the kindergarten transition. In addition, the KIC has proven to be more than a series of informational workshops. One of the unique and powerful outcomes of the KIC is the community of on-going family support that it builds. As the content of each session builds upon the last, the connections and friendships formed within the cohort grow, forming a community of parents who can support each other as their children move through the transition process and beyond.

The Cohort is currently in its fourth year. Parents who graduated in the first three years report that the skills learned in the Cohort were instrumental in helping their children gain access to the general education classroom. Classroom teachers report that Cohort graduates are empowered advocates who come prepared to partner effectively with schools to help meet the needs of their children.

For more information please visit our website at www.allbornin.org or email Alicia at alicia.kindergartencohort@gmail.com. Due to the nature of the sessions, space is limited, so please sign up today!

Have a great summer and we hope to see you in the fall!

Learn more about the Kindergarten Inclusion Cohort and apply online at allbornin.org

Bike First!

Bike First! just finished its 2013 bike camp, and there's a whole group of new riders on the roads just in time for summer! Ann Donaca-Sullivan has been running the camp here in Portland since 2006, and enjoys much local support for this great program. In the spring of 2013 Ann approached the NWDSA and asked if we would be interested in partnering with Bike First!, and we were thrilled to do so.

This spring Bike First! received the first inaugural Impact Award from the Multnomah Athletic Foundation, honoring the organization and how it has made a difference in our local community. From the Multnomah Athletic Foundation:

The Multnomah Athletic Foundation proudly announces the first inaugural Impact Award. Each year this award and an accompanying grant will be presented to a nonprofit organization in the Greater Portland community. This award recognizes an organization that impacts its community through promoting athletic participation.

About Bike First!

Typically developing children learn to ride a bicycle with help from their family and friends. Unfortunately, most individuals with disabilities who try this route are unsuccessful. Through many years of careful research into the elemental physics of bicycle riding, Dr. Richard Klein, a retired mechanical engineering professor at the University of Illinois, and his team designed and built a unique type of adapted bike that enables the rider and bike to function together as a system. Bike First! works with youngsters and adults who experience difficulty getting past training wheels and onto conventional two-wheelers.

Stronger Together

for Looking another educational opportunity for parents of children age birth - 5? This spring we launched Stronger Together, a collaboration between the NWDSA and Early Childhood Special Educators Molly Hulett and Holly Ingram. The free, cross-disability workshops are held monthly during the



school year and are designed to provide current, best practices ideas and skills to parents of children age birth-5 with developmental disabilities.

The first two workshops were on using visual supports in the home, and supporting communication in young children. We will be working this summer to create a program for next year's workshops, and the information will be posted on the NWDSA website. For more information, please contact Molly at mhulett@nwdsa.org or call (503) 238-0522.









Each board member of the NWDSA has firsthand experience with the joys and the hardships of caring for a child with individual needs. We understand the importance of connecting with other families and how much we rely on these relationships when we encounter the inevitable challenges. We also celebrate each others' victories, making the journey so much richer. The Board of Directors of the NWDSA consists of volunteers and is supported by enlightened professionals. For more information on our organization and ways in which you can become involved or make a donation, please visit our website at www.nwdsa.org or call (503) 238-0522.

Para comunicarse en español, llame a Sheyla Hirshon at (503) 239-1509 o Isis Sanchez, (503) 442-5817



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A PDF of this newsletter and past issues are available for download at www.nwdsa.org

Promotoras

Con gran entusiasmo, la Asociación Noroeste de Síndrome de Down (NWDSA) anuncia un nuevo proyecto para formar un grupo fortalecido de madres y padres Hispanos que podrían desempeñarse como "promotoras" en apoyo de otras familias. Aunque la NWDSA abre sus puertas incondicionalmente a todas las familias, comprendemos que nuestras familias inmigrantes enfrentan barreras particulares para involucrarse, entre ellas diferencias de idioma y cultura, mas el poco conocimiento del sistema de servicios educativos y de sociales en Oregon.

Esperamos agilizar su camino juntando un grupo de padres para recibir conocimientos y fortalecer su liderazgo, para que luego apoyen a otras familias en su vecindario y ayuden a construir una comunidad de familias bien unidas e informadas, capaces de aprovechar los eventos del NWDSA y servir como apoyo mutuo. Rosa Flores coordinará el proyecto con el apoyo de Sheyla Hirshon y la junta directiva de NWDSA. Si tiene preguntas o quiere participar, favor de comunicarse con Abby al #503-238-0522 o abraithwaite@nwdsa.org.

The NWDSA is excited to announce a new project to build an empowered group of Spanish-speaking parents to work as "promotoras" supporting Hispanic families in a parent-to-parent model. While the NWDSA unconditionally welcomes all families, we understand that our immigrant families face special barriers to involvement, including language and cultural differences and a general unfamiliarity with the educational and social system.

We hope to address this by bringing parents together for educational sessions, empowering them as leaders to go back out to families in their region and help build an informed, connected community of families who access existing NWDSA events and also support one another as needed. Rosa Flores will head this project, with the support of Sheyla Hirshon and Abby Braithwaite and the NWDSA Board of Directors. If you have questions or are interested in participating, please contact Abby at abraithwaite@nwdsa.org or (503) 238-0522.



Et Cetera

... The new NWDSA website launched in March after months of work by webmaster Joni DeRouchie and Abby Braithwaite. New features include a new parents page, event calendar, and extensive resources pages full of great reading material and downloads. Take a look around at www.nwdsa.org and if you wish to pass along feedback or requests, please email jderouchie@nwdsa.org and share your thoughts. We would love to hear what you think!

... Our Amazon Affiliate Program is a fun, new way to contribute to the NWDSA while shopping on Amazon! Just visit the Recommended Reading page on the website at http://www.nwdsa.org/ds_resources/recommended_reading.html and click on one of the links to go shop on Amazon. A portion of your sales will kick back to us, no matter what you buy during your shopping session!

... Are you fluent in another language? We periodically get calls from families and providers needing support for families who are not native English speakers. If you can help with this type of support, please contact Abby Braithwaite at abraithwaite@nwdsa.org or call (503) 238-0522. We would love to have your help!

... The NDSS Times Square Video Project deadline is July 10th, so get your photos submitted today! Every year, NDSS kicks off Down Syndrome Awareness Month with a special video presentation on a jumbo screen in the heart of the Times Square. Learn more at www.ndss.org.

Events • full calendar at www.nwdsa.org

Weekly community and All Born (In) drop-in hours are suspended through the summer. Please call (503) 238-0522 for an appointment.

Open Arms Playgroups: Join other parents and their children for an opportunity to ask questions, share ideas, and learn from others' experience.

Portland Open Arms Summer Potluck: Tuesday, July 9th, 5:30 - 7:30 PM. Molly & Chris Hulett will host the 2nd Annual Open Arms in the great outdoors at their home in Oregon City. Call (503) 238-0522 for info and to RSVP.

Vancouver: Second Sunday of every month from 3:30 - 5:30 PM at Steamers & Screamers, 8400 NE Vancouver Mall Loop, Suite 105, Vancouver WA.

Open Arms will be suspended during the month of August but will be back in full force in September!

Club Upside Vancouver: Second Saturday of every month, 2:00 - 4:00 PM, St. Andrew Lutheran Church, 5607 NE Gher Road, Vancouver WA.

Photo Exhibit Benefit: Wednesday, July 17th, 7:00 PM at Analog Lounge, 720 SE Hawthorne, Portland OR. Local photographer and parent Jared Holmgren showcases photos of children from the NWDSA community.

Summer Social: Sunday, July 21st at Lee Farms, 21975 SW 65th Ave, Tualatin OR.

RLC Workshop on gross motor development: Saturday, September 7th at Resurrection Lutheran Church, 1700 NE 132nd Ave, Portland OR.

Buddy Walk: Saturday, September 28th at the Rose Quarter Commons



Angela Jarvis-Holland Executive Director

NWDSA Board of Directors: Steven Holland Abigail Braithwaite Angela Jarvis-Holland Angela Frome Becky Adelman Guiseppe Lipari Michelle Wallace

For more contact info please visit www.nwdsa.org or www.allbornin.org

The NWDSA is organized for charitable, scientific & educational purposes to provide families and individuals with Down syndrome social opportunities, support, education and information.

The NWDSA is a registered non-profit corporation in Oregon and has 501(c)3 tax-exempt status with the federal government.

Down syndrome is a genetic condition that occurs in approximately one of every 691 live births. The chance of having a baby with Down syndrome is not affected by where you live, social class or race. Having a baby with Down syndrome does not mean you did anything wrong: nothing done before or during pregnancy causes Down syndrome. In recent years, our community has seen incredible success in school, community and employment that would have been hard to imagine a generation ago. High expectations, coupled with appropriate supports, allow our children to live full, rich lives as contributing community members.



Join us at

California Pizza Kitchen

for a flavorful FUNdraising event!

Just bring in this flyer, present it to your server, and 20% of your check will be donated to our organization. Purchases include dine-in, take-out, catering and alcoholic beverages!

Fundraiser in support of

NW Do<mark>wn</mark> Syndrome Association July 29-August 2

(All Day)

California Pizza Kitchen

Clackamas Town Center •
11840 SE 82nd Ave, Happy Valley
(Next to Sears)
503-659-0760

Go to cpk.com to view our pizzas, pastas, salads, appetizers & desserts. You can even order online!

Join the CPK Adventure Club at cpk.com and receive \$5 off your next visit!



Eligible groups include non-profit schools and 501c organizations. Donation amount excludes proceeds from tax, gratuity, gift card and retail purchases. Valid for dine-in, take-out, online orders, catering or curbside service. Alcoholic beverages included. Not valid on delivery. Event proceeds void if flyers are distributed in or near the restaurant.

Manager, please attach this flyer to the guest check.