



UCP Oregon Annual Report

THIS IS OUR LEGACY





WE ARE UCP OREGON.

We support people who experience intellectual/developmental disabilities. We've been advocating for real choice, real jobs, real homes, and real connections since 1955. This is our legacy. Read on to learn more.

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From the Desk of Michael Steen, UCP Oregon Board President

Dear Friends,

UCP Oregon is approaching our 65th anniversary. As ever, we're steadfastly focused on advancing a Full Life, inclusive of independence, productivity, and full citizenship, for people with cerebral palsy and other intellectual and developmental disabilities.

The specific components of a Full Life will vary for each person. However, it is rooted in respect for individual choices, well-being of mind and body, and fostering connections. That's why UCP recently hosted multiple focus groups, consisting of a cross-section of UCP customers and their families/caregivers.

We asked the following questions:

- What does UCP do well?
- What could UCP do better?
- What is UCP not doing that we could do to help realize a Full Life?

Although we received a full spectrum of answers, there were common themes: people seek services that support interconnectivity and self-determination. We used these themes to help us determine the key focus areas of our next multi-year Strategic Plan.



We are focusing on:

- Full Life services
- Diversifying funding
- Enhancing community partnerships
- Advocacy

With enthusiasm—and your continued engagement—we will shepherd UCP Oregon in the years ahead. We invite you to reach out in any way to further our partnership together.

Kind regards, Michael

OUR SERVICES



Supported Employment

UCP's Supported Employment Department ("Employment Solutions") assists job-seekers who experience disabilities to find meaningful jobs in the community. Once the customer has the job, we can provide initial trainings and on-going supports as needed—all with the goal of ensuring the customer is as independent as possible.



Supported Living

Adults who experience developmental disabilities use our Supported Living services ("Foundations") to live independently in their own homes. We provide whatever is needed, including quick check-ins, medical or financial oversight, or round-the-clock staffing.



Children's Services

UCP's Children's Services Department ("Building Blocks") offers one-on-one supports, both at home and in the community, for families raising children who experience developmental disabilities. Services include personal care, skills training and community inclusion. Building Blocks also offers support groups for siblings of children who experience disabilities.



Brokerage Services

Our Brokerage Department is known as "UCP Connections" for a good reason--these services are all about connecting adults who experience disabilities to the resources they need, including funding and service providers. We also provide person-centered planning and case management.



Family Support

And, in honor of our roots, our Family Support Department offers unique services to families who experience cerebral palsy, such as information and referral, support groups, recreational outings, and a sense of connection and hope.

UCP'S MISSION:

To advance the independence, productivity, and full citizenship of people with cerebral palsy and other disabilities.



UCP VALUES

Inclusion:

Individuals are included in every aspect of life including home, school, workforce, and community.

Empowerment:

People with disabilities, and families of children with disabilities, have a right to make decisions about things that affect their lives. We help them identify their options and utilize the same means as anyone else in the community to achieve their goals.

Family Solidarity:

Families having a member with disabilities are supported so they may stay together and flourish.

Teamwork:

It takes teamwork to produce positive results. The many people who contribute to our mission are appreciated, encouraged, and supported.

Diversity:

All persons are valued and respected for their individual differences.



From the Desk of Ann Coffey, Executive Director



LEGACIES

I have had the privilege of working within UCP of Oregon for nearly sixteen years! I have learned so much over these years: to move through my life in a way that is open and curious; to seek understanding and connection; and to speak out and stand up for diversity, inclusion, equity, and truth.

Most importantly, I have learned to celebrate the unique and valuable contributions ALL humans present. I can truly say that I am a better person for having spent so many years in the presence of UCP Oregon and the individuals we support.

My hearts aches as I say goodbye to some of our lifelong customers, employees, volunteers, board members, and donors who have, or are, facing their final days. Death with dignity has become a high priority at UCP Oregon. Unfortunately, it is always difficult to ensure that individuals are honored at end of life; the resources provided never seem to be enough.

As they approach the end of life, many of

our customers need more funding and family/community supports. We work incredibly hard to find enough supports, but the broader system isn't set up to ensure a comfortable transition. This year, I have found myself working especially hard to shed light on this cruel part of the disability service delivery system.

I have also been working to focus on the legacy that is left behind. Each of our customers brings so much to the human experience, and to their communities as a whole.

We must spread awareness and inspiration. We must ensure that people with disabilities are visible, respected, and treated with the love and consideration they deserve. And we must work to ensure that approaching the end of life isn't a time of confusion, struggle, and distress. Instead, it should be a time of laughter, reminiscing, celebration, and connectivity.

It's been a deeply powerful, tough, and exciting year. Thank you for being part of it.

Cordially yours,
Ann



A LIFETIME LEGACY:

Jerry Pattee, Board Member & Advocate

By Michael Steen, UCP Oregon Board President, 2018-2019

As some of you know, I experience cerebral palsy. So, too, did Jerry Pattee, a long-standing UCP Oregon board member who recently passed away.

Jerry was an impactful, kind and gentle mentor to UCP board members—and anyone, young or old, who experienced developmental disabilities. He connected people across diverse circles, always with the intent of creating a more resilient community. I am blessed to have walked, rolled, shared stories, and laughed with him for the past ten years.

Jerry was born and raised in Portland. He spent his entire adult life working in the telecommunication industry. In 1985, he began using his skills as a natural leader on UCP Oregon's Board of Directors. Over the

decades, he served in nearly every board capacity, including serving as Board President three times, and, most recently, as Board Historian. Jerry was proud of UCP's supports. As he said, "UCP's advocacy for system change and social equity for people with disabilities is unparalleled!"

Jerry was a major force in the larger community as well. He served on several disability-related advisory groups, including the Oregon Self Advocacy Coalition; Community Partners Council (OHSU); Committee on Accessible Transportation (TriMet); Oregon Office on Disability and Health (OHSU); and the Portland Commission on Disability (City of Portland).

Jerry passed away in April, 2018 at age sixty-four, and will be dearly missed.







WHAT UCP HAS MEANT TO ME

By Susan Cushman, Outgoing Family Support Director

EDITOR'S NOTE: Susan Cushman has been UCP's Family Support Director since 2006. She retired in July of 2019. Susan, you will be missed more than we can say!

It was 1992. My daughter was only four months old, and I was at the doctor's office, being told that she had cerebral palsy (CP). That day was one of the most traumatic I've ever lived through. At that point, I didn't even know what CP was. I didn't know how I was going to get

through this, parenting a child with a disability I knew nothing about. Luckily, the doctor who diagnosed her was a UCP board member. She gave me the card for UCP's Family Support Director.

I called UCP the next day, and the woman who answered the phone was the parent of twins with CP. She knew exactly what I was going through, and reassured me that I



"Parents joke that we belong to a club that no one asked to join."

--Susan Cushman, Former Family Support Director

could do this, and that she was there for me any time I had any questions or concerns. I called her often!

I have been connected to UCP ever since. I attended every Family Support Conference since they began in 1996. I was at UCP's first parent support group meeting in 1998. I went to every family outing. I took advantage of UCP's "Respitality" services to get overnight breaks from caregiving. I also frequently received support from UCP's Family Support Director, interacting with three of them over the next decade. And, in 2006, I became the Family Support Director.

My favorite part of the job is talking with other parents, especially the new moms who call right after their child gets a diagnosis. I've never forgotten how hard that is, and I'm grateful that I have become a source for reassurances, resources, and helping parents make connections with other parents.

When I took over the position, we ONLY supported families who had kids with cerebral palsy, and we "aged out" families when their children turned twenty-one. I realized, however, that there is very little out there for young adults with disabilities, so I stopped aging out families. We also began welcoming families who had children who experienced genetic or chromosomal anomalies that were similar to CP, since these families often had no support.

Medical and therapeutic communities are a great resource. But, what we as parents find is, parents know best. Only another parent knows what it's like to wade through Individual Education Plans, therapy appointments, Developmental Disability services, stares from strangers, rude questions, and well-meaning but hurtful comments. Parents joke that we belong to a club that no one asked to join.

We created a closed Family Support Facebook group that allows us to share equipment, resources, information, and ask questions of each other. When a family gets a surgery recommendation, the parent can ask the group what their

experience with that surgery was. When a piece of new equipment is recommended, parents borrow that equipment from another family to try it out. This is a community of support unlike anything else.

One of the most dramatic examples happened when a mom posted about her 10-month-old baby. He'd already had multiple surgeries, and had been given many labels. The mom asked what his future would hold. Almost instantly, seventeen moms replied.

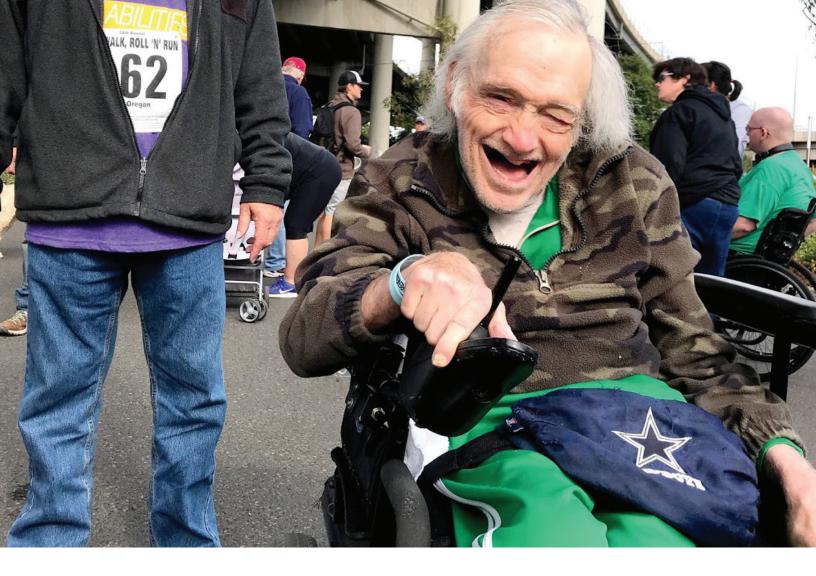
I realized I needed to capture the conversation—all ten pages of it! I edited it down to a two-page document called "Advice to New Parents," which we give to every new family. It's a hopeful, yet realistic document. Parents might be hearing from doctors that a child won't ever walk—and maybe they won't—but maybe they will. Experience has proven that high expectations are better for our kids than dire warnings.

Our kids get labels, but they aren't defined by their labels. When my daughter was eleven, she was on the "Growing Up with CP" panel at the UCP Family Conference. Near the end of the workshop, UCP board member Jerry Pattee asked a question: "If you could wake up tomorrow without CP, would you want to?" My daughter replied, "No. CP is all I've ever known, and I like who I am."

While being the Family Support Director is my "job," I often say it is an extension of my life. I have been privileged to have a job I truly love. Looking back, I am most proud of the play I and five other UCP moms wrote and produced ("Fierce Love"), as well as the presentation I created about the unique grief process experienced by many parents of children with disabilities.

I never expected to be in this position for thirteen years! It's been wonderful, but I am now ready to turn the baton over to the next parent. I'm a ceramic artist and look forward to spending a lot of time in my studio, hopefully with others who want to come play with clay with me.





SIMPLE HUMAN GOODNESS:

John Calhoun's Legacy

By Charlie Russell, Former Personal Assistant to John Calhoun

EDITOR'S NOTE: Many of you have been saddened to learn about the recent passing of a long-term UCP customer, John Calhoun. John was a tireless disabilities rights educator and citizen advocate.

John Grant Calhoun arrived in this world on July 7, 1935, departing again more than eighty-three years later on March 5, 2019.

Ordinarily, given such a long life, any of us might have left some memorable impressions.

John, however, left a truly remarkable legacy by having demonstrated how simply an exceptional life may be led.

All of us experience "disability," or personal hindrances of some sort. Particular challenges

"He simply lived in genuine human goodness and decency. A more compassionate and caring person none of us are likely again to meet."

--Charlie Russell, Former Personal Assistant to John Calhoun



were an inescapable fact of John's life due to brain damage caused during birth.

But his life was not defined by cerebral palsy. A spirited navigation through the entirety of life gave his its meaning. The inspiration of John's legacy shines through his example in a life challenging to us all.

Naturally charismatic, John was an adroit teacher who spoke about living with extraordinary challenges, addressing audiences at local universities and national conferences. Moreover, he taught by his everyday example, shown to all those around him. A gentle man, he purposefully touched the lives of as many people as possible.

I was fortunate to receive gifts of a more intimate experience than others enjoyed. For over eleven years, John ensured that I had a place in his home, most often as live-in companion, and in others roles, too. My friendship with John was one of the dearest I've ever known.

By firsthand witness, I came to understand John's life as exemplary. I saw that emanating from nothing particularly fancy, or complicated. He simply lived in genuine human goodness and decency. A more compassionate and caring person none of us are likely again to meet.

John's mind as I knew it was uncluttered by self-centered thought; his heart as I felt it unbound by many of the weaknesses to which we are all too prone. I trust his soul persists now as it once did while he was yet among us in body, nobly defiant of any limitation or obstacle.

I daresay John would have taken an enthusiastic part in forming UCP's vision for 2020 and beyond. He can, still. John Calhoun's legacy remains a beacon illuminating our way.



A LEGACY LIVES ON:

The Bill Porter Memorial Fund

UCP Oregon launched the Bill Porter disabilities. With persistence and confidence, Bill convinced Watkins Inc. to give him a door-

prove his worth.

Memorial Fund in 2018 in an effort to remove barriers and support meaningful lives for people experiencing disabilities.

Bill Porter exemplified the mission and values of UCP Oregon. Bill was born in 1932 and was diagnosed with cerebral palsy. For many years, he found himself unable to gain employment due to public misperceptions of

It was a tough job—Bill often found himself walking eight to ten miles per day, a significant challenge for an individual

to-door salesman job—an opportunity to

By Gavin Johnson, Development Director

impacted by cerebral palsy.

Nonetheless, Bill became Watkins' top salesperson, and worked for them for over forty years. Bill's story spread throughout the nation from articles in *The Oregonian*, ABC's 20/20, and even an award-winning movie, *Door to Door*.

Bill Porter passed away in 2013. The UCP Oregon Board of Directors committed to honoring Bill's legacy. The Bill Porter Memorial Fund (BPMF) was launched.

The UCP Oregon Board designated \$250,000 to seed the fund, pledged annual giving amounts to grow the fund, and agreed to match the first \$250,000 that is raised from donations with another \$250,000 from UCP Oregon's investment portfolio. Our ultimate goal is to reach a BPMF principal balance of \$1,000,000.

The BPMF recently accepted our first round of applicants. Below are some of the first success stories!



Bonnie

Bonnie is a teen who wanted more privacy and independence; she requested an attachment for the commode. As she said, "I have to have someone help me in the bathroom. I just turned 15 and this is embarrassing to me."

Nowadays, though, it's a very different story; as Bonnie's mom says, "Bonnie smiles as she shuts the door to use the bathroom on her own."





Samantha

Samantha is two years old, and has a serious heart defect and cerebral palsy. Her family will be using their BPMF funds to purchase a "scoot" bike for her. Samantha will be able to improve her balance in a safe and fun way, and—for the first time ever—she'll be able to take an active role in family bike rides. As Samantha's mom says, this purchase will "for sure put a smile on her face all summer."

Gracie

Gracie is a joyful 11-year-old girl who loves to be anywhere that her family and friends are, cheering them on. She is involved with Special Olympics, 4H, and a swim team. She's going to be using her BPMF funds to purchase a family membership to a local aquatic center. As her mom says, "It's been so exciting to finally find a physical activity that the entire family can do together!"

David

David will be using his BPMF funds to take classes from a local photographer. As David says, "Being able to take photos would allow me to feel more independent, since it is something I can do on my own, and would give me the ability to break away from my day-to-day routine. It would also open the door to a new hobby and allow me to show off my art to others."

Andrew

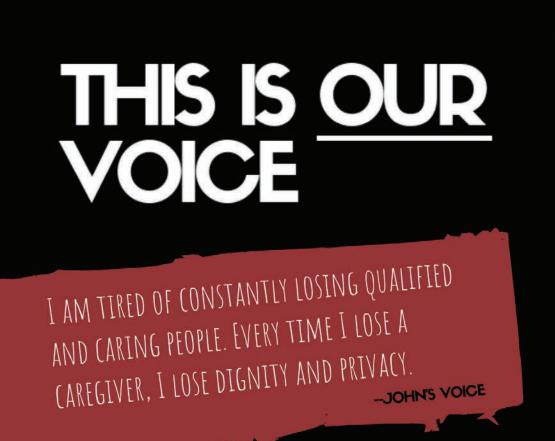
Andrew experiences cerebral palsy... and a panic disorder that is triggered by loud noises or environments. He's going to use his BPMF funds to purchase powerful noise-cancelling headphones. As he says, the headphones will "allow me to cope better with my panic attacks and not force me to leave activities due to noise" and "have better peer interactions."

Kimberley

Kimberley finds that she doesn't get out of her apartment as much as she'd like. She'll be using her BPMF funds to take swimming lessons at a nearby community pool. She'll be able to socialize and, as she says, be "active without pushing my body too hard."

David (the other one!)

David experiences autism, and is attending college, with the goal of eventually working with a technology firm to develop better prosthetic devices. We're excited to be assisting him with funds towards tuition, fees, books and supplies.



STORIES FROM
ACROSS OREGON'S
INTELLECTUAL/
DEVELOPMENTAL
DISABILITIES
SERVICES

A WORKFORCE IN CRISIS

By Corrie Hausman, Marketing Coordinator

I'm frustrated. I'm sad. I'm angry.
I'm afraid. I feel like I'm about to fall
off a cliff.

These are scary words.

And yet these are words that everyone in the disabilities world is hearing a lot these days. Both customers and the people providing supports feel like they're at the edge of a cliff, due to an ever-growing, nationwide, caregiver shortage.

Simply put, there aren't enough qualified

caregivers. Positions go vacant for weeks or months. Many of the seasoned caregivers are leaving to work in other fields because they can't pay their bills or afford healthcare.

John Griffiths experiences developmental disabilities, and has been supported by several agencies over the years, including UCP Connections, UCP Oregon's support services brokerage. He and his UCP Personal Agent work together to hire Direct Support Professionals / Personal Support Workers (DSP's / PSW's). John's PSW's support him to have a clean house, get out



John adores one of his caregivers in particular. He describes her as "loving, compassionate, caring, sensitive, thoughtful, and patient. She has helped me go beyond what my parents, my

into the community, and manage his health and safety.

teachers, and even I thought I could do."

This caregiver found and facilitated an internship for John at a local arts collaborative, and also helped John create an emotional support group.

Alas, this wonderful caregiver is having a hard time staying in the field. She needs health insurance, a retirement plan, better pay, and paid time off. John worries that she will leave her job or the field entirely.

This isn't an unreasonable fear. Over the years, John estimates that he has had around 25 caregivers, one of whom only lasted two weeks before getting a better paying job elsewhere. He's also experienced turnover in case managers.

John says he's "tired of losing people." He is tired of having poorly trained or poorly skilled caregivers. He's also tired of dealing with position vacancies. When John doesn't have supports, he doesn't get out of the house. He doesn't socialize. He finds himself getting sick and anxious.

John has made complaints through official channels, but it seems to him as though the state will take ten years to come up with a solution. But ten years is too long. "We're at the ledge," he says. "It's just a matter of time until people start falling off."

That's why John went to UCP Oregon's Executive Director, Ann Coffey. She had been experiencing the same issues—but as an employer. As she says, "Entities that employ caregivers are losing their best and brightest to Starbucks, McDonalds, and other entry level retail and service jobs. It's essential that we have funding in order to pay a competitive wage."

"We're at the ledge. It's just a matter of time until people start falling off."

> --John Griffiths, UCP Customer and Self-Advocate

They decided to take action. They ended up creating a project called This Is Our Voice, with the goals of (1) collecting stories from the workforce and those receiving supports, and (2) assisting anyone involved to advocate at every level.

So far, they've attended numerous local and statewide disability events, and appeared on a local radio show. They also worked with a website designer to create a website that makes it easy for anyone to share their own personal experiences of the workforce crisis.

Maybe, someday, with continued effort, we won't be hearing, I'm sad. I'm angry. I'm afraid. I feel like I'm about to fall off a cliff.

Instead, maybe we'll be hearing, We did it. Our voices were heard.

Like John, are you at the edge of the caregiver crisis? Do you have something to say? Share your story with us: https://www.ucpaorwa.org/our-voice.html.







TELLING THE UCP STORY

By Matthew Aldapa, Development Coordinator

UCP Oregon has spent the last sixty-plus years running "lean and mean." We pride ourselves on providing meaningful and efficient services while spending very little money on administrative costs.

In 2017, however, we decided it was time to properly build out our Development Department. We hired a Marketing Coordinator and a Development Director, with the idea of growing our events (especially the Walk, Roll 'n' Run; more on this later) and telling the UCP Oregon story a little more effectively. A year later, we added a Development Coordinator to the mix.

And just in time, too... in, 2019 UCP's "Walk, Roll 'n' Run" celebrates 15 years of bringing

together families and friends! There will be a fun-filled walk, and a more intense 5k run, along the Willamette waterfront. Participants form teams, fundraise, volunteer, and increase community awareness about UCP's mission and services. The event takes place on Saturday, September 21, 2019.

2019 is also the year that the national UCP organization is celebrating "75 years" of United Cerebral Palsy. UCP Oregon is, of course, part of their yearlong celebration. UCP Oregon also celebrated our own long history at our 2019 "Friends Breakfast," presenting on our own six-decades of advocating for the civil rights and

independence of people who experience disabilities.

We're also investing in new, inclusive events that appeal to UCP's diverse customers and supporters. We created fun activities like "Dine-Outs" (where customers, supporters and employees all dine at a restaurant to raise money for UCP); Blazers and Thorns games (where a portion of the ticket sales go to UCP); and the always popular indoor skydiving. These events are open to anybody who wants to attend, not just UCP customers or caregivers. This ensures that people with—and without—disabilities have the opportunity to meet and bond. We hope to see you at an event soon!



THANK YOU, DONORS





\$50,000+

Oregon Community Foundation

\$10,000-\$49,999

- OCF Joseph E. Weston Public Foundation
- Oregon ABLE Savings
- Samantha Richardson

\$5,000-\$9,999

- Carole Lietzke
- Paulson Coletti Trial Attorneys PC

\$1,000-\$4,999

- Cheryl Adams
- Peter Blasco, M.D.
- Jack & Michelle Bradley
- David Brezinski
- Beneficial State Bank
- Country Financial
- Scott Greenland
- Huggins Insurance
- JD Fulwiler & Co
- Kaiser Permanente
- Law Offices of Nay & Friedenberg
- Megan McCarthy

- William Miles
- Miller Nash Graham & Dunn LLP
- Moss Adams
- Network For Good
- Cherie Nomura
- Relay Resources
- Jane Sassalos
- Stephen's Place
- Emily Stockman
- Mission Bar-B-Que
- Beneficial State Bank
- United Access
- US Bank Charitable Services

\$500-\$999

- Lawrence Benedict
- Alex Brandon
- Marc Carlson
- The Cheerful Tortoise
- Nancy Cicirello
- Jeffrey Couttouw
- Custom Ink LLC
- Christine Grant
- John Hancock
- Hudson Charitable Trust
- Eric Newell
- Permobil



- Portland Parks & Recreation
- Kimberly D Price
- Philip Rothrock
- Michael Steen
- Megan Stratman
- Steve Zalkin

\$250-\$499

- Amy Alberts
- Mark Allred
- Amazon Smile
- Beaches
- Julianne Davis
- Michael Deen
- Samantha & Timothy Dexter
- Kyle Eason
- Ron Friesen
- Chris Fromhart
- Give with Liberty
- Sean Heaton

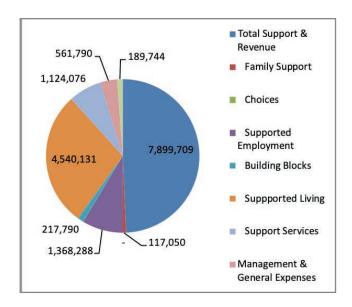
- Miriam Joffe-Block
- Gavin Johnson
- Rachel Kennedy
- Steve King
- Kroger
- Kianna Lamont
- Marilynn Luchini
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- Massachusetts Life
- Jim & Teresa Marie McGuire
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- Susan Porter
- Stephanie Ruttert
- Emily Smith
- Stormbreaker Brewing
- Trail Blazers Inc.
- Thomas & Levinia Valencia
- Colleen Welsh
- Willamette Lodge No. 63 International Association of Machinists

UCP FINANCES





TOTAL SUPPORT & REVENUE	7,899,709
PROGRAM EXPENSE	
FAMILY SUPPORT	117,050
CHOICES	
SUPPORTED EMPLOYMENT	1,368,288
BUILDING BLOCKS	217,790
SUPPORTED LIVING	4,540,131
SUPPORT SERVICES	1,124,076
MANAGEMENT & GENERAL EXPENSES	561,790
FUNDRAISING EXPENSES	189,744
TOTAL EXPENSES	8,118,869
TOTAL LIABILITIES AND NET ASSETS	6,614,312



UCP Oregon (formerly United Cerebral Palsy of Oregon & SW Washington) offers individualized supports, information, and advocacy for people with cerebral palsy and other developmental and intellectual disabilities and their families. We've been committed to improving supports for people experiencing disabilities for over 60 years.

Our mission is to discover new ways to assist the people we support to lead a meaningful and fulfilling life, full of personal choice and rich in community experiences and relationships.

To your left is an overview of UCP Oregon's income and expenses for the fiscal year which ended 6/30/2019.

We are proud to show that 92% of our expenses go to support our services, while only 8% is used for administrative and fundraising costs.





UCP LEADERSHIP



Board of Directors

Officers:

- President: Michael Steen, Beneficial State
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- Vice President: Jerry Hoffert, Albertina Kerr
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- Secretary: Megan Stratman, Northwest Requirements Utilities
- Board Historian: Jerrold Pattee, Jr. V1
 Datacom, Inc

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- Julianne R. Davis, Lane Powell (retired)
- · Leslie Adams, Performance Mobility
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- Nancy Cicirello, PT, MPH, EdD, School of Physical Therapy, Pacific University
- Peter Blasco, MD, Child Development and Rehabilitation Center, Oregon Health & Science University

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Brokerage Director:

Sarah Noack

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John Goff

Development Director:

Gavin Johnson

Employment Services Director:

Melissa Miller

Family Support Director:

- Susan Cushman (outgoing)
- Katherine Ball (incoming)

Finance Director:

Esther Large

Human Resources Director:

Suzannah Newman, JD, PHR

