

CARE SERVICES CONNECTIONS

SPRING & SUMMER 2023

ALS
ASSOCIATION
Oregon and
SW Washington
Chapter

LEGACY BUILDING

We all create a legacy that our loved ones will remember us by. Your legacy could be something as simple as a favorite family recipe, cherished family photograph, a recording of a conversation about what is important to you, or even handwritten letters to close friends or family members. These memories are examples of legacy projects: a meaningful piece of work that someone creates for those they care about. Legacy projects can serve as a reminder of who you are and what was important to you.

Creating a legacy for your loved ones not only gives you the opportunity to share and honor the precious memories and events that have shaped who you are but can also be therapeutic and allow you to reconcile difficult memories or experiences. Below are some legacy project ideas to consider.

Create a video montage of your best advice, your most cherished memories or stories about yourself or family members. A video can be made using a smartphone, video camera, or with the help a business like: Memories Live (www.memorieslive.org), Artifact (www.heyartifact.com) or Storyworth (welcome.storyworth.com).

Write a poem or song created specifically for you or your loved one. (See examples at songfinch.com, songlorious.com, songheart.com, songlystudios.com)

Make thought Rocks with images or words on them painted or written by you. Place your stones in small jewelry bags or fancy boxes and give the stones to your loved ones. You can also add these stones to a memory garden.

Whatever type of legacy project you decide to do, it should be personal and unique to you and should hold meaning to you since it will serve to continue your bond with your loved ones. **For more ideas about different legacy projects, reach out to the Care Services Coordinator in your region.**

POETRY LEGACY

Written by Person living with ALS, Karen Stiles

Soon after my ALS Diagnosis I began to think about my grandchildren -how might they remember me? What would be my legacy?

It didn't take me long to decide to continue in the tradition of my grandma whom we affectionately called "Enee". Included in a small collection of poetry she wrote for her family, are seven poems written about each one of her grandchildren. As a family it is one of our most beloved keepsake



Karen with her "littles" - Jaxon & June

POETRY LEGACY

CONTINUED

possessions. Although “Enee” passed when I was five, I still feel her presence and love every time I read her poems. She captured my essence in her poem, and it always takes me back to being with her.

I currently have four grandchildren and have started writing poems for each of them. I started with my oldest grandson Parker and then completed

one for Paige, his younger sister. I am currently writing for my “littles” Jaxon and June. I hope they will find my love and special place I have for each of them through their poems. In the future, may the poems bring comfort and connection each time they read them and enjoy remembering how much they were loved by “Nana”!



Parker, Nana 'Karen', Paige, and daughter Alison

LEGACY BUILDING: THE ZIEGELE FAMILY EXPERIENCE

When Dale and Judy Ziegele of Ridgefield, WA, received Dale’s diagnosis of ALS in September of 2022 at the age of 79, their focus changed.

Dale and Judy have been married for 56 years and have an extremely close relationship with their children and grandchildren. Dale worked as a youth director, pastor and has had a passion for helping people throughout his career and life. One of the vitally important things Dale did right away was to bank his voice, on the urging of his son, Jon Ziegele, an occupational therapist who also works with ALS patients.

Dale, Judy, and their family recognize the importance of legacy building and moved quickly to begin this process after his diagnosis. Dale’s daughter in law April Ziegele subscribed to a group called Artifact, a service that offers professional interviews and edits the interviews into podcast length recordings that can be shared with others.

Later, Dale and family reached out to family friend, Heidi Blake from Wisconsin, who had lost her father to ALS three years prior to Dale’s diagnosis. After a brief text exchange, Heidi and friend, Ally Payne, volunteered to fly to the Pacific Northwest to record Dale’s stories.

Heidi and Ally’s involvement in this project has not only made a difference for the Ziegele family, but also had a considerable impact on Heidi and Ally themselves.

“The journey that we’ve gone on to document Dale’s story has been extremely meaningful for those involved and to me personally. The love that Dale has shared with so many has had a trickle-down effect, which is displayed in this video, which in turn will inspire others to share that love as well.”- Heidi Blake

One of Dale & Judy’s sons Paul Ziegele shared the impact that this project has made on



Dale and Judy Ziegele

him and some tips he has learned along the way. "Hearing the stories of my parents' life has reinforced my values and priorities. It has made me reconsider where I invest my time in ways that matter most."

Paul's tips for others wanting to try a similar legacy project process include:

- **Using a good microphone** – "I can't emphasize how important it is to use a good microphone to capture the best quality audio and not have the distractions of background noise."
- **Consider who's asking the questions** – "Since most people are so relationally oriented, they aren't likely to be successful just turning the camera or the audio recorder on by themselves. It is SO IMPORTANT for people to relationally connect with someone when they are telling their story. This advice was so helpful for us and came from an ALS caregiver support group – get the grandkids to ask the questions!"
- **Think about how your stories could include closed captioning (CC)!** "After my dad's diagnosis, my grandma, Fay Ziegele, celebrated her 100th birthday. Her hearing isn't that great. To make sure she could see and hear some of what was going on, I transferred some of the raw video recordings to DVD and hard-coded the closed-captions on the screen so she could follow along. Sharing the video with CC was a way for her to come to grips with his diagnosis, and also to participate in the uplifting stories."
- **Get started today.** "Don't let technology uncertainty or concerns about making a perfect video get in the way of doing something now to make or document a memory. I often ask the question 'Five years from now, what will we want to remember about today?' to frame our priorities. We have been very fortunate to have the time and the strength of dad's voice – don't waste those chances!"

Read more about the Ziegele family's experience at alsoregon.org/ziegele-family

NEW VOLUNTEER PROGRAMS HAVE LAUNCHED

Our goal at The ALS Association & SW Washington Chapter is to help make the lives of people living with ALS and their families a bit easier through volunteer assistance, as well as to offer an outlet where volunteers can bring their energy and talents to help the ALS community.

Helping Hands Program

We understand that living with ALS makes daily tasks more challenging. To make life a little bit easier, we are offering the Helping Hands Program. Through this program, we match trained volunteers with families affected by ALS to assist with tasks like chores, meal prep, running errands, or being a friendly visitor.

Mentor Support Program

Mentors offer empathy and solidarity as people who have "been there."

For caregivers, the best support often comes one-on-one from those who are on the same journey. The Mentor support program will connect those who are new to or currently serving as caregivers with those who have previously cared for a loved one with ALS.

To volunteer, receive a volunteer, or learn more, please visit www.alsoregon.org/volunteer

If you have any questions, please reach out to our Volunteer Coordinator, Kristi Snyder at kristi.snyder@alsoregon.org or 971-277-5388

We welcome ideas or feedback on these programs as they were designed for you, and we would love to know your thoughts!

ALS SUPPORT GROUPS



Support group is a meaningful way for people living with ALS and their caregivers to connect, and a significant way our care service team supports People living with ALS and their care network. Chapter-wide we host around 20 groups a month to provide a space for education and facilitated discussion.

Steve Florin shares that he attends group for the sense of community, "I appreciate listening to individuals who share the same concerns about their disease." He adds "I can't say that I enjoy the meetings, but I usually leave feeling better than when I came."

For people living with a rare disease, like ALS or PLS, support group may be the first place they meet another person with the same diagnosis. Nancy Triffilo, who attends multiple groups a month, says, "I enjoy these groups because everyone knows what I'm going through. I don't have to explain it again."

Support groups allow the chapter to share information about living with ALS, but more importantly it allows People living with ALS and their family members, friends, and caregivers to learn from each other.

Another regular attender, Rhonda Bauman, echoes this idea, "There are no Lone Rangers in life, especially when you have ALS, No one understands me better than the ones who have been walking in the same shoes I am."

Motor neuron disease causes progressive weakness and disability, making it increasingly difficult for someone living with MND to get out of the house. Our many virtual options allow participation from home and with a variety of adaptive communication tools.

Thank you for sharing this space and your stories!

For more information visit alsoregon.org/support-groups or speak with your local care coordinator.

"The places in which we are seen and heard are holy places. They remind us of our value as human beings. They give us the strength to go on." Rachael Remen

NEW MEMBER OF THE CARE SERVICES TEAM



Rebekah Albert, the Chapter's Bereavement Services Coordinator, joined the team in December 2022 to expand the chapter's bereavement and grief programs.

Rebekah has served in a variety of roles in the nonprofit world over three decades, including The YMCA of Greater Seattle, The Humane Society of the Willamette Valley, The Meals on Wheels People, Rose Haven, and Northwest Family Services. Rebekah is a past recipient of the Spirit of Portland and YWCA - Women of Excellence awards.

Rebekah is delighted to have this opportunity to further develop the chapter's bereavement services for families and individuals impacted by ALS.

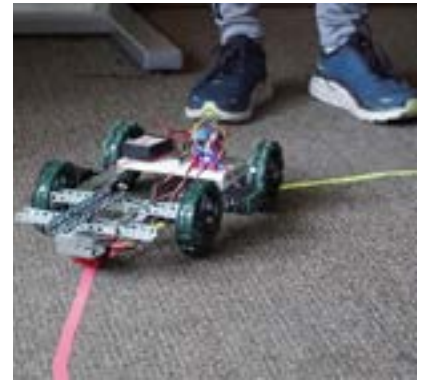
For more information, you can reach her at Rebekah.albert@alsoregon.org or by phone 503-573-8823.

AAC CORNER

Earlier this year, ALS Association Care Services team members Susan and Ashley had the pleasure of collaborating with students enrolled in Tech for a Better World at Riverdale High School in Lake Oswego, Oregon. Susan and Ashley presented to the class on multiple occasions, with topics ranging from general information about ALS, assistive technology, and augmentative and alternative communication (AAC), and common barriers that people living with ALS face as their disease progresses. Brian Epp, a tech extraordinaire and person living with ALS, also presented to the class and offered his perspective and answered questions from the students.

Under the guidance of educator Adam McLain, students first researched ALS and current assistive technologies to gain an understanding of barriers people face and areas for innovation. Once projects were selected, the students worked in small teams to bring their ideas to fruition. The projects included a computer mouse and wheelchair controls that can be accessed through small EMG sensors that detect electric signals from muscles in the arms, a program that can track eye movements using a built-in desktop camera, sensors that can detect an object and alert the driver if their chair is too close to prevent collisions, and wheelchair sensors that allows the chair to follow a set path without collisions.

The students' dedication and enthusiasm for developing new technologies that are cost-effective and benefit people living with ALS is encouraging. The ALS Association is grateful to the students at Riverdale High School, Adam McLean, and Brian Epp for their contributions.



PROGRAM UPDATES

Learn about these programs and more at alsoregon.org/navigating-als

ALS Chapter Grant Program

Our chapter offers grant opportunities twice a year to help people in Oregon and SW Washington cover the high costs of living with ALS. The Chapter Grant Program helps people with ALS/PLS/PMA and their caregivers cover the cost of co-pays, respite care, communication devices, home modifications, and other reimbursable expenses.

Virtual Education Series

We offer informative presentations on topics related to living with ALS. These calls take place on a regular basis and are open to people living with ALS, caregivers, friends, or those interested in learning more about ALS. Miss the last presentation? No problem! You can view past presentations on our website - visit the link above.

Caregiver Bootcamp: October 16 - 20

Being the primary caregiver for a loved one living with ALS can be stressful. In addition to being on call 24/7, caregivers may have additional responsibilities, like working and taking care of children. Participants in our weeklong Caregiver Bootcamp will come away from the event with the trusted, vetted support they need to care for their loved one. Save the dates for October 16-20 and stay tuned for more information later this year.



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THANK YOU TO OUR YEAR ROUND PARTNERS



YOUTH RESOURCES

Learn more at alsoregon.org/support-and-resources-for-children

Resources for Youth impacted by ALS:

The Dougy Center is a Portland-based nonprofit organization that provides grief support in a safe place where children, teens, young adults, and their families can share their experiences before and after a death. www.dougy.org.

Hope Loves Company is a nonprofit organization that provides emotional and educational support to children and young adults impacted by ALS. They offer camps, virtual meet ups, resources, and activities for children, teens, and young adults. www.hopelovescompany.org.

Youth Action Day: May 13, 2023

Youth Action Day is an opportunity for kids, teenagers, and young adults across the country to take a stand against ALS! Pick a challenge or create your own idea! Find more information about how to get involved at alsoregon.org/get-involved/als-youth-challenge

Scholarship Opportunity

The Jane Calmes ALS Scholarship Fund's annual program is open and accepting applications through May 18, 2023! The fund was established to support post-high school education for students impacted by ALS and its financial burden on their family. Scholarship recipients receive up to \$5,000 per year to help cover the cost of pursuing an accredited undergraduate college degree or vocational certificate. For more information visit, als.org/get-involved/jane-calmes-als-scholarship-fund.

Family Day Events - Save the dates

Join in on a fun day for the whole family. Children, Teens, Grandchildren, and Kids at heart are all invited to participate! This is a wonderful opportunity to meet others and have some fun.

Portland Metro Family Day: Saturday, October 7 - OMSI

Southern Oregon Family Day: Saturday, September 16 - TBD

Willamette Valley Family Day: Sunday, October 15 - Newport Aquarium

Central Oregon Family Day: Saturday, September 23 - TBD