

Alzheimer's Resource of Alaska

SUMIDA: LIFE WITH LEWY BODY DEMENTIA

A personal account of daily living with Lewy Body Dementia by Connie Sumida

Lewey Body Dementia with Parkinson's has changed our lives from that of an average middle age couple looking forward to years full of adventure to a life as disabled retirees

Steve was a brilliant man. He could do anything. He could look at a problem and visualize the solution in one glance, whether that problem was building a trailer (complete with welding, wiring and carpentry) or showing a village the legal way to do their own police work. In his work life he was a lawyer, grant writer, and executive director of

various native groups. Lewey Body Dementia with Parkinson's changed all that.



Pictured: Connie and Steve Sumida

Because the first thing to go with Lewey Body Dementia is the executive functions, Steve lost his ability to plan right away. He could not even write a coherent paragraph or letter so he lost his job right away. Now he struggles to find the first step to any project and the second or third step is beyond his comprehension. However, he does keep constantly busy with projects, it just takes him a long, long time to get anything started, let alone finished.

He is currently building a tree house in a dead tree in the back yard; even with difficulty in measuring and conceptualizing, he perseveres. His perseverance did *(Cont.)* page 3

FROM TRASH TO TREASURE: EXOSOMES COULD SHAPE A BLOOD TEST FOR EARLY DETECTION OF ALZHEIMER'S

Exosomes—tiny particles that are produced by all types of cells and circulate in the bloodstream—could be the basis for a blood test to diagnose Alzheimer's disease about 4 years before noticeable symptoms emerge. The results from a study led by NIA Intramural Research Program (IRP) scientists were reported July 15 in JAMA Neurology.

Exosomes, also known as extracellular vesicles, were dismissed for decades as cellular trash. The tiny vesicles have since been found to communicate cellular messages over long distances and carry valuable information in their cellular cargo of proteins,

metabolites, lipids, and nucleic acids. Scientists are researching these biochemicals in order to gather information about health and disease in various body systems.

The NIA team has been exploring the potential of neuronal exosomes as "windows to the brain" with the potential to be a low-cost, minimally invasive way to distinguish healthy people from those in the early stages of Alzheimer's disease. Current methods to help diagnose Alzheimer's disease are expensive and involve radiation (positron emission tomography) or require a lumbar puncture to analyze cerebrospinal fluid. In this study, they examined several

years of blood samples from 350 participants (average age, 78), including 128 who eventually developed Alzheimer's, and 222 who remained cognitively normal. They isolated neuronal exosomes and found that those with larger diameters and higher levels of phosphorylated tau protein successfully predicted Alzheimer's disease about 4 years before noticeable symptoms developed (with an average accuracy of more than 80 percent). (Cont.) page 3

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Letter From The Executive Director

Dear Friends,

When gasoline was \$1.10 a gallon, Ronald Reagan was president and "Terms of Endearment" was the Best Picture, Alzheimer's Resource of Alaska was formed. Quite a bit has changed in our world since 1984, but the passage of 35 years hasn't altered our commitment to the original vision of our founders, Beck Clement and Beverly Tallman.



I hope many of you can join us in celebrating that vision and our longevity at our 35th Anniversary Party on November 1, 2019 at the Anchorage Sheraton Hotel. "Dinner Drinks and Jazz, a fundraiser featuring Melissa Bledsoe Fischer" will kick off November, a month designated "Alzheimer's Disease Awareness Month" as well as "Family Caregiver Appreciation Month". There's more information about the Anniversary Party as well as other awareness activities on our website. If you're viewing an electronic version of this newsletter, click here to learn more.

Most of you know that our Care Coordination program delivers case management services to hundreds of clients experiencing dementia, frailty and other disabilities from our locations in Mat-Su, Juneau and Anchorage. For many, navigating the web of services and supports that make it possible to live in one's home or community can be an overwhelming process. Last year's satisfaction survey of all care coordination clients resulted in an amazing 100%

I recommend to you the front page article written by a caregiver who on page 3 agrees with me that, in her words, "I am not alone. Alzheimer's Resource of Alaska is, to me, the home of my friends...they are there if I need a kind word or a shoulder to cry on."

As ever, I thank you for your support.

Sincerely,

Pamela Kelley Executive Director





SUMIDA: LIFE WITH LEWY BODY DEMENTIA

A personal account of daily living with Lewy Body Dementia by Connie Sumida (Cont. from page 1)

not change with the dementia and I think this will help him to remain more normal for a longer period of time than most people with dementia



A painting by Steve from 2018.

My life now revolves around Steve. I am his rock. Without me around he becomes more anxious and his dementia becomes worse. He does not go anywhere alone, so I have to go everywhere with him. He used to do all the driving, now I have to. He can no longer assist with making family decisions, leaving that burden to me. It is like having a child again who needs my time and attention, but he will never grow out of it, he will become as a younger child as time goes by.

But there is no cloud without a silver lining! Steve has always had a wicked sense of humor, but without social filters (which dementia takes away) he is hilarious! The subtle comments from Steve keep us in stitches. Also, Steve and I get to spend a lot more time together than we would have if he had continued to work.

"My life now revolves around Steve. I am his rock."

Due to anxiety issues, we cannot travel but we can play Pokémon

Go and sit together to "read." Steve and I have always been close but we are closer now than ever. Alzheimer's Resource of Alaska has been a great help in these times of trial. We started going to Art Links and Steve began painting again. We attended Mind Matters support group until Steve's anxiety became too great. For me, going to these events helps me to see that others are having the same emotional, psychological, and physical struggles that I have. It is encouraging to know I am not alone. Alzheimer's Resource of Alaska is, to me, the home of my friends Pam, Anne, Debbie, Kim, and Lavonda. They are there if I need a kind word or a shoulder to cry on.

Getting an early diagnosis can greatly change the Alzheimer's or dementia journey. Don't know where to start? We can help by doing a free memory screening.

To celebrate Alzheimer's Awareness month this November, we will be doing free memory screenings around the state this fall. See location and date information below.



10 am - 3:00 pm

Fairbanks Office 565 University Ave., Ste. 2 Tuesday, October 29 10 am - 4:00 pm Juneau Office 3225 Hospital Dr. Wednesday, December 4 Noon - 6 pm Wasilla Senior Center 1301 S. Century Cir. Thursday, November 14 10 am - 3:00 pm

FROM TRASH TO TREASURE: EXOSOMES COULD SHAPE A BLOOD TEST FOR EARLY DETECTION OF ALZHEIMER'S (Cont. from page 1)

The team then validated the biomarkers using 64 samples (average age, 73) from the Johns Hopkins Alzheimer's Disease Research Center.

The scientists view these findings as further evidence for neuronal

exosomes as a potential key to a low-cost, noninvasive blood test for Alzheimer's. Future goals include combining these with additional exosomal biomarkers to determine a model for predicting Alzheimer's and other neurodegenerative diseases.

Reference: Kapogiannis D, et al. Association of extracellular vesicle biomarkers with Alzheimer disease in the Baltimore Longitudinal Study of Aging. JAMA Neurology. 2019. Epub July 15. doi: 10.1001/jamaneurol.2019.2462.

Individual & Business Contributors

These contributions received between July 1 - September 30, 2019

Active Network, LLC Alan and "Beth" Joy Adrian Alaska Fur Exchange Alaska Travel Industry Association Fairbanks Alpha Hawk Amber D Wright Anchorage East Rotary ASD Charitable Giving Campaign Barlow Anderson, LLC Carole Kristy Gray Charlene Walker David E Stevenson via **Dovon Utilities** Dan Gavora via Dovon Utilities

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Starbucks *Abbott Road Susan Alaska Cox

Ann W Farris Tom Iskra



Professional Webinars

Connect via zoom; please register for link. To register, contact Amber Smith by e-mailing asmith@alzalaska.org.

Alzheimer's Diesease and Related Dementias Tuesday, October 22 Noon - 1:00 PM

Person-Centered Care Tuesday, November 19 Noon - 1:00 PM

The Power of Music Tuesday, December 10 Noon - 1:00 PM

Mental Health First Aid for Older Adults

Join us for an accredited nursing educational opportunity that goes over how to identify, understand, and respond to mental health issues and the unique needs of adults over the age of 65. Free to attend, however, registration is required.

Anchorage 1750 Abbott Road Monday, November 11 8:30 am - 5:30 pm

Wasilla 777 N. Crusy Street, Ste. B101 Monday, November 18 8:30 am - 5:30 pm

To register, contact **Kevin Silver at** 907-561-3313 or e-mail ksilver@alzalaska.org. Please plan on bringing your own lunch.

In Honor & Memory of

Jack Bacher Mary Lou Bacher

Joe Essert Jill A Cubbedge & Georgia K Holton

Jane Hammond Pioneers of Alaska Women Kristen & Connor Igloo #11

Dan Ilgenfritz, Pard Richards, Muriel Cramer, Ran Malstron Bert M & Betsey A Sharp

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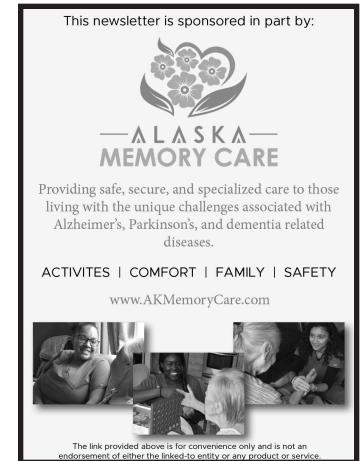
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Interested in reaching out to Alzheimer's Resource of Alaska's friends? Consider sponsoring an ad in this newsletter. We have many other sponsorship opportunities as well. Every sponsorship dollar stays in Alaska and is used to forward our mission to: "support Alaskans affected by Alzheimer's disease, related dementias and other disabilities to ensure quality of life."

Call us today at 561-3313.



ALZHIEMER'S RESOURCE OF ALASKA

is proud to present our new Chorus comprised of singers living with Alzheimer's or related dementia, their care partners and volunteer "Choral Friends"

"Voices of the Last Frontier" In Concert

Sponsored by



November 22, 2019 • 1:30 PM Wilda Marston Theater in the Z.J. Loussac Library

\$12 General Public, \$10 Seniors age 60 and up Get your tickets today! Call 907-561-3313 or visit us at 1750 Abbott Road, Anchorage

Classes & Events around the state

ANCHORAGE

1750 Abbott Rd., 561-3313

ABC Presentations

Memory Cafe Presentation Monday, 10/7 10-11:30 am or 5:30-7 pm

Overview of Dementia Monday, 10/21 10-11:30 am or 5:30-7 pm

Assistive Technology of Alaska (ATLA) Presentation Monday, 11/4 10-11:30 am or 5:30-7 pm

Care for the Caregiver Monday, 11/18 10-11:30 am or 5:30-7 pm

Anchorage Fire
Department Presentation
Monday, 12/2
10-11:30 am or 5:30-7 pm

Do I Need a Care Coordinator? Monday, 12/16 10-11:30 am or 5:30-7 pm

Savvy Caregiver Reunion Tuesday, 11/12 5:30 - 7:30 pm

Virtual Dementia Tour Wednesday, 10/23 10-4 pm Registration is required.

Brain Works Tuesdays, 10/29-12/17 10:30-11:30 am

Mind Matters I Tuesdays, 10/29-12/17 1-2:30 pm

Mind Matters II Wednesdays, 10/30-12/18 10-11:30 am

Mind Matters III
Thursdays, 10/31-12/26
10-11:30 am

See page 4 for our professional offerings **Registration Required

MAT SU VALLEY

777 N. Crusey St., St. B101, 746-3413

ABC Presentations

Overview of Medicaid Waiver Monday, 10/14 1-2:30 pm or 5:30-7 pm

Introduction to Adult Guardianship Monday, 10/28 1-2:30 pm

PAC "Normal" Aging vs "Not Normal" Aging Monday, 11/11 1-2:30 pm or 5:30-7 pm

The GEMS** Monday, 11/25 1-2:30 pm or 5:30-7 pm

Joyful Moments, Meaningful Activities Monday, 12/9 1-2:30 pm or 5:30-7 pm

Awareness Presentation
Wandering & Dementia
Monday, 11/4
10:30-11:30 am
(Takes place at Sunshine
Community Health Center
in Talkeetna)

Art Show & Open House Tuesday, 10/7 1-4 pm Registration is required.

Brain Works
Wednesdays, 10/16-12/11
1:30-3 pm
Registration is required.

Mind Matters Wednesdays, 10/16-12/11 10:30-Noon Registration is required.

Art Links

Anchorage 1750 Abbott Road Every Friday, 11 am - Noon

Mat-Su 777 N. Crusey Street Suite B101 Every Friday, 1-2:00 pm

JUNEAU

3225 Hospital Dr., 586-6044

ABC Presentations

Being the Decision Maker Wednesday, 10/23 12-1:30 pm or 5:30-7 pm

The Holiday Season & Dementia Wednesday, 11/13 12-1:30 pm or 5:30-7 pm

Movie: Complaints of a Dutiful Daughter Wednesday, 12/11 12-1:30 pm or 5:30-7 pm

Savvy Caregiver Thursdays, 10/17-11/21 5:30-7:30 pm Registration is required.

Virtual Dementia Tour Tuesday, 11/1, 10-5 pm & Wednesday, 11/2, 9-4 pm Registration is required.

Free Memory Screenings Wednesday, 12/4 Noon-6 pm Registration is required.

Memory Cafe

An opportunity for persons living with dementia and their care partners to socialize and enjoy entertainment with peers.

Anchorage

Anchorage Senior Activity Center 1300 E 19th Ave Every 2nd Thursday 1 - 2:30 PM

Wasilla

Wasilla Area Seniors, Inc. (WASI) 1301 S Century CIR Every 3rd Tuesday 1 - 2:30 PM

FAIRBANKS

565 University Ave., #2, 452-2277

ABC Presentations
Overview of Alzheimer's

Diesease Tuesday, 10/15 5:30-7 pm

Virtual Dementia Tour Tuesday, 10/29 10-4 pm Registration is required

Free Memory Screenings Wednesday, 10/30 10-4 pm Registration is required.

Our Fairbanks location will have a limited schedule this fall, due to circumstances beyond our control. We will resume normal scheduling for Fairbanks in January. We apologize for any inconveniences. For questions, please call us at 907-561-3313.

Caregiver Webinars

Connect via Zoom; please register for link.
To register, contact
Gay Wellman: 822-5620 or gwellman@alzalaska.org.

Holidays & Travel Wednesday, 10/9 10:30-Noon Saturday, 10/12 1-2:30 pm

The GEMS** Wednesday, 11/6 10:30-Noon Saturday, 11/9 1-2:30 pm

Meaningful Activities Wednesday, 12/11 10:30-Noon Saturday, 12/14 1-2:30 pm

Savvy Caregiver Saturdays, 11/9-12/14 10 am - Noon

**The GEMS is a model curated by Teepa Snow that teaches how individuals can shine over the course of their Alzheimer's or related dementia journey.



Caregiver Support Groups around the state

A safe place for caregivers, family and friends of persons with dementia to share experiences and solutions.

| Location | Date & Time | Contact |
|---|---|--|
| Statewide Telephone Support Group | Every 1st Saturday, 1-2 pm Every 3rd Wednesday, 1-2 pm | Dial in using 1-877-216-1555, Code #927989. For additional information, contact Gay Wellman, 822-5620 or 800-478-1080x5 |
| Anchorage | | |
| Alzheimer's Resource of Alaska, 1750 Abbott Road | Every 4th Thursday, 5:30-7 pm | Debbie Chulick, 561-3313 |
| Eagle River | | |
| Holy Spirit Episcopal Church, 17545 N. Eagle River Loop Road | Every 2nd Thursday, 5-6:30 pm | Debbie Chulick, 561-3313 |
| Fairbanks | | |
| Alzheimer's Resource of Alaska, 565 University Ave. Ste. 2 | Every 2nd Tuesday, 5:30-7 pm Every 3rd Tuesday, 11:30-1 pm | Joan Adams, 452-2277 |
| Homer | | |
| Homer Senior Center | Every 2nd & Every 4th Thursday, 2:30-3:30 pm | Pam Hooker, 235-7655 |
| Ketchikan | | |
| Ketchikan Senior Center, Upper Level | Call for current schedule. | Bernice, 255-8080 |
| Kodiak | | |
| Kodiak Senior Center, 302 Erskine Avenue | Every 4th Thursday, 12:30-1:30 pm | 486-6181 |
| Mat-Su Valley | | |
| Alzheimer's Resource of Alaska, 777 N. Crusey St., Ste. B101 | Every 2nd Tuesday, 1:30-3 pm | Janice Downing, 746-3413 |
| Palmer Senior Center, 1132 S. Chugach Street | Every 1st Friday, 10-11:30 am | Kim Jung, 746-3413 |
| Primrose Retirement Community, 889 Elkhorn Drive | Every 3rd Thursday, 10-11:30 am | Janice Downing, 746-3413 |
| Seward | | |
| Seward Senior Center | Every 4th Thursday, 1-2 pm | 244-5604 |
| Sitka | | |
| Brave Heart Volunteers 120 Katlian Street | Call for current schedule. | 747-4600 |
| Soldotna | | |
| Soldotna Senior Center | Every 2nd and Last Tuesday, 1-3 pm | Judy Warren, 262-1280 |
| Sterling Senior Center | Every 1st Tuesday, 1-2 pm | Judy Warren, 262-1280 |
| Talkeetna | | |
| Sunshine Community Health Center 34300 Talkeetna Spur Rd. | Every 1st Monday, 10-11:30 am | Janice Downing, 746-3413 |
| Willow | | |
| Sunshine Community Health Center 24091 Lake Long Rd. | Every 1st Monday, 1:30-3 pm | Kim Jung, 746-3413 |

Not seeing a support group that's right for you? Give our Education Department a call at 907-561-3313. We'll be happy to help you find the right solution for you.



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Alzheimer's Resource of Alaska celebrates our 35th anniversary with:

Dinner, Drinks and Jazz

Featuring the jazzy sounds of Melissa Bledsoe Fischer

November 1, 2019 from 6 - 10 pm at the Sheraton Anchorage Hotel

Get your seats today!

\$75 per person.

Call 907-561-3313

or go to:

www.alzalaska.org/dinner-drinks-jazz

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