

30 Years of Care and Connected Hearts

Thirty years ago Ronald Reagan was President. *Terms of Endearment*, a heartrending story about mothers, daughters and loss, won the Academy Award for Best Picture. Two American astronauts became the first humans to make an untethered spacewalk. Nineteen Eighty-Four was also the year that two Alaskan sisters formed what would eventually become known as Alzheimer's Resource of Alaska.

No one intends on journeying down the difficult path that Alzheimer's Disease presents to patients and families alike. But Sisters Rebecca Clement and Beverly Tallman felt themselves very much untethered and alone as they searched for answers, information, assistance and comfort in seeking ways to care for their beloved mother, diagnosed with Alzheimer's at the age of fiftytwo.

In 1978 the sisters had to transport their mother from Anchorage to Seattle to receive a basic diagnosis of Alzheimer's disease. The disease was identified and named in 1906, and yet there was no independent national non-profit organization dedicated to making an effort against Alzheimer's until 1980. The possibility of obtaining a

diagnosis of Alzheimer's disease anywhere in this country was difficult at best; in Alaska it was nearly impossible. The doctors in Seattle had little advice for caregiving beyond the diagnosis.

Little was known and less was disseminated regarding the care for Alzheimer's patients; this was a disease as mysterious as it was pervasive. Six years after Ronald Reagan left office he would announce to the world that he was suffering from Alzheimer's, a stark warning to the entire nation that not knowing about the disease did not mean you were out of its reach.

Today, it is projected that in Alaska there are approximately 8,000 people living with Alzheimer's Disease or related dementias. The support system that currently exists for Alaskan families touched by Alzheimer's would be almost unimaginable to a family in the same circumstance in 1984. And yet, Rebecca and Beverly did imagine a future where families would not be alone in the struggle to care for their loved ones.

The plan was as powerful as it was fundamental, a desire to honor and care for their mother even as they lived their own lives.

Caring for a person with early onset Alzheimer's is never less than daunting, doing so before there was a name for it amounted to a succession of closed doors and dead ends. Raising their own families, working jobs and financing the care of their mother led Rebecca and Beverly to the conclusion that they could not be alone in this struggle. There must be other Alaskans like themselves looking for a better way of caring for loved ones who cannot care for themselves.

A grassroots movement was born when the South Central Counseling Center put the sisters in touch with a social worker looking to complete her Master's degree by facilitating a Caregiver's Support Group. A handful of caregivers came together, compared notes, shared experiences and proved that initial hunch to be on target: they were not alone.

With an early and incisive decision to focus on Alaskans suffering from Alzheimer's, the next obvious move was to find out where these individuals were and who their caregivers were. There was no playbook. Resources were pooled and a grand total of

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(907) 822-5620

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Toll Free within Alaska (800) 478-1080

www.AlzAlaska.org

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Letter from the Executive Director

Dear Friends,

As we celebrate our 30th year we reflect on our mission: *To unite Alaskans affected by Alzheimer's disease and related disorders to ensure quality of life until a cure is found.* By the very nature of our mission we are a forward looking organization and so it is with great interest that we stay current with efforts of other organizations, scientists, agencies and individuals striving to alleviate the burdens inflicted upon those affected by Alzheimer's Disease and

Related Disorders (ADRD).

It is interesting to note that more than thirty years ago our founders Rebecca Clements and Beverly Tallman had to take their mother out of state for a diagnosis of Alzheimer's disease. Today, Alaskans are vastly better informed and better positioned to benefit from the resources and expertise surrounding ADRD; due in great part to Alzheimer's Resource of Alaska. Nevertheless, the need to expand services and create innovative solutions to the devastating problems posed by Alzheimer's Disease continues.

The numbers are daunting; an estimated 44 million people worldwide suffer from ADRD, a number set to almost double every twenty years. In addition to the emotional and physical toll, the world-wide economic cost of the disease is roughly \$640 billion dollars a year. The G8, the group of industrialized nations, has made a public commitment to find a cure or therapy for ADRD by 2025. "Mutual efforts to stimulate and harness innovation at the global level need to be strengthened. Consequently, we call for greater innovation to improve the quality of life for people with dementia and their caregivers while reducing the emotional and financial burden," because in ADRD we are facing, "one of the greatest enemies of humanity."

The challenge is immense, but so is the promise of innovation and new technologies in terms of treatment, therapy and a possible cure. Our commitment to looking and leaning forward takes concrete form this fall as we host the two day conference: Vision to Reality – Breaking Barriers, Embracing Diversity, Growing Together. This conference is discussed in greater detail on page 6 of this newsletter, as well as through regular updates on our website: AlzAlaska.org.

In keeping with a forward looking spirit, I would like to recognize our newest board members. Returning to the board is Ken Acton, a self-employed Aviation Consultant and a longtime supporter of the organization, first serving as a board member in 1991. Retired Executive Assistant Nancy Jones volunteered with us before becoming a board member in 2001. Nancy returns to the board after a one year hiatus, an interval where she still found time to serve on our Nominating Committee. Natasha Pope is the Community Relations Manager at First National Bank of Alaska and joins us for her third term as a board member, first serving in 2007. While away from the board, Natasha lent invaluable support to the Finance Committee. Lynn Van Vactor, from Dillingham, is the Executive Director of Washington and Alyeska Vocational Services; an organization that provides support and rehabilitation to persons experiencing disabilities and barriers to independent life in Alaska and Washington. This exceptional group of volunteers brings to our organization a continued dedication to serving frail elders and those with ADRD throughout Alaska.

Best regards,

Karl Garber

Executive Director

Redesigning Long Life

Today, more people are living longer than at any time in human history. Adapting our culture to this rapidly aging population will put entire societies to the test. The Stanford Center for Longevity is at the forefront of efforts to meet the challenge of making certain that quality of life keeps pace with increasing lifespan.

Commercial technological innovations too often overlook a segment of the population that might benefit from it the most, the elderly. This past April, the Center for Longevity sponsored a Design Challenge showcasing the talents of young designers intent on revolutionizing how we solve the problems of aging.

The inaugural Design Challenge put students to a particular test by demanding that they "design new solutions that will keep individuals with cognitive impairment independent for as long as possible."

The top two prize winners of the Design Challenge didn't reinvent the wheel, but they did reimagine the spoon.

A research and design team from the National University of Singapore made a winning impact by taking a practical look at the mysterious relationship of taste, memory and emotion. They came up with the Taste+ Electronic Spoon.

The taste of a long lost recipe can evoke memories of childhood, of family, friends and even places. That the lust for life can be extended and enriched by so basic a human need as flavor proved an insight worth exploring to the Singapore team.

Scientific research has long recognized the mysterious and persistent link between memory and taste. The Singapore team harnessed this mystery for a practical solution to a problem that has long vexed care givers.

A pervasive problem in caring for those affected by Alzheimer's and related dementias is malnutrition. Taste sensitivity can become severely diminished and make a person less likely to enjoy and consume an entire meal.

Taste+ is essentially a "smart" spoon that stimulates and simulates taste sensations on the tongue. Two simple buttons on the spoon's handle are connected to electrodes at the tip of the spoon, one for sour and the other for salt. Like increasing the volume on a remote control, a few presses of the spoon handle can liven up an otherwise bland tasting chicken soup. The tongue is fooled, but the belly is not.

The joy of a good meal brings vitality to life.

The Taste+ spoon is non-invasive and draws on recently developed digital tasting technologies. Sweet, minty and spicy tastes can be created through thermal simulation – but are not yet incorporated in the Taste+ spoon. Not commercially available at this time, Taste+ is

TASTE +

2 Silver Electrodes

Non-conductive plastic

Embedded LEDs

Button view

making the push from laboratory to the dining room in the near future. The cost is projected to be around \$40.

Continued on Page 5...

TECHNOLOGY & AGING

Notable Websites

longevity3.stanford.edu

The Stanford Center for Longevity
Scientific and technological
research into Mind, Body and
Mobility solutions to the problems
of aging.

aginginplacetech.com

A comprehensive blog covering the latest products, trends and tech research.

aging2.com

Aging 2.0 educates and connects innovators in an effort to improve the lives of older adults.



Connected Hearts continued from Cover

\$300 comprised the entirety of the budget for the first outreach effort. Newspaper ads were placed across the state, from Cordova to Kotzebue, asking for any information from those caring for people who might have Alzheimer's or related dementias.

In an age before cellphones and the internet, the responses came at a trickle. But they did come – a statewide conversation had begun, a mission born and the need to create a non-profit became apparent.

Rebecca says of the individuals in the business community who helped in the official formation of Alzheimer's Resource of Alaska: "The whole success of the organization is because of the grassroots we always had – a connection in our hearts. We found the right people with the right answers who had some personal connection to someone who had the disease."

The State of Alaska almost immediately recognized the new non-profit with a \$28,000 ADRD Education and Outreach grant - a crucial commitment in the creation of support services for caregivers.

In a distinctly Alaskan fashion, the all-volunteer force went on a bush storming tour of Alaska, disseminating information, providing referrals, trainings, consultations and establishing support groups. In short, letting Alaskans touched by ADRD know that they weren't alone in the effort to care for their loved ones.

Where there were once closed doors and frustration, there are now offices in Anchorage, Fairbanks, Juneau and the Mat-Su Valley that seek to provide support and information. The Medicaid Waiver Program, grant funding, advocacy in the State Legislature, support groups, Art Links, a decade of Amblin' for Alzheimer's walks and a tireless team of staff, board and volunteers – the particulars of Alzheimer's Resource of Alaska's mission are multifaceted, but the core of the mission has been consistent for thirty years.

Rebecca recounts a moment toward the end of her mother's life that goes to the very core of why the Alzheimer's Resource of Alaska was conceived. "She sat at the piano and put her hands on the keys. Suddenly, she began to play like she did when I was a child...Don't make decisions in a crisis. Seek the best services in the moment – because the moments will change. The road is terribly bumpy but you don't want to miss that last song."

Long Life continued from page 4

Another winner, Shao Yao of the Academy of Art in San Francisco was inspired to enter the Design Challenge because of an intimate connection to a grandmother who suffered from Alzheimer's disease.

While many Alzheimer's sufferers, and elderly persons in general, compensate for loss of taste by an unhealthy tendency to over salt or season their food; some suffers of dementia find the dining experience frustrating enough to avoid eating altogether.

Yao saw first-hand how a loved one's dignity at meal time can be of paramount importance. She designed a seven piece tableware set branded as "Eatwell". Utensils with extended and curved handles, non-slip bowls molded for ease of use and colors that make meals appear more inviting impressed the Design Challenge judges enough to earn Yao a first place award of \$10,000.

Yao's elegant, durable and thoughtful designs serve a real utility and contribute to that essential element of every memorable meal: ambiance. Caregiver and diner are able to focus on the joy of eating rather than the mechanics.

The mind is enlivened through the essential pleasure of taste and the body is strengthened by consistent nutrition.

Whether driven by altruism, compassion or market forces, the Tech Industry looks to be trending toward a new focus on the particular problems of aging.



Vision to Reality

Breaking Barriers, Embracing Diversity, Growing Together

A Two Day Conference

In celebration of 30 years of service, Alzheimer's Resource of Alaska invites you to mark your calendars and join us in attending: *Vision To Reality*. This two day conference located in Anchorage on November 12th and 13th of this year, will be a heartfelt examination of what divides us and brings us together as human beings in the challenge of formulating a best practice in dementia care. Internationally renowned dementia and senior care expert, Dr. Bill Thomas, is fast becoming known as the "Dr. Spock" of aging through his revolutionary and visionary reshaping of traditional notions of eldercare. In his words, "The boomers are creeping toward elderhood, and I aim to help explain the terrain." Dr. Thomas will bring his considerable talents as a physician, author, storyteller, musician and farmer in exploring a vision for Alaska's aging population and those affected by ADRD. Day two will feature an assortment of breakout sessions tackling lesser known issues associated with ADRD, including Cultural Diversity and Sexuality. Also on Day Two, a discussion with Jocelyn McGee, M.S.G., Ph.D. and Assistant Professor of Psychology at the University of Alaska, Anchorage. A Neuropsychologist and Geropsychologist, Dr. McGee will speak about the latest innovations in non-pharmacologic care techniques. Visit AlzAlaska.org for more details, continual updates and registration information.

Mat-Su Grant Renewed

In 2010, the Mat-Su Health Foundation awarded Alzheimer's Resource of Alaska a \$300,000 grant (\$100,000 per year for 3 years) to provide respite and chore services for frail elders and those with ADRD in the Mat-Su Valley. We recently finished the third year of the grant and applied for 3 more years of funding. The Mat-Su Health Foundation found great value in the services we provide for the fastest growing population of seniors in the state. The grant will fund 3 more years at \$135,000 per year, for a total grant of \$405,000. We are honored to continue to partner with the Mat-Su Health Foundation to serve those in need in the Mat-Su Valley.

Thank you to everyone who has chosen to Pick.Click.Give. in support of Alzheimer's Resource of Alaska!





We would like to thank the generous participants in our 10th annual Amblin' for Alzheimer's this past May. We have so many to thank for making this year's walk a great success! With your contributions, the event raised more than \$60,000 for our programs and services.

We are the only organization in Alaska specializing in Alzheimer's disease, ensuring that all of your tax-deductible contributions stay in Alaska to support Alaskans! Alzheimer's Resource of Alaska cannot do what it does without the generous commitment of a caring community. Thank you again for your thoughtful support of Amblin'.

We would like to thank the following sponsors for their contributions of cash, food, and prizes that make our walk special:

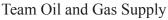














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Memorials & Tributes

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Mother's Day

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In Honor of

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Chugiak Lions Club

To go paperless, email us at contact@AlzAlaska.org to sign up for electronic delivery of this newsletter, training opportunities and other announcements.



Classes around the state

For information on any of these classes or programs visit www.AlzAlaska.org/events or contact the office nearest you.

ANCHORAGE

1750 Abbott Rd. 561-3313

- Is It Alzheimer's Disease? 10AM-12:00PM OR 5:30-7:30PM Monday, August 25
- Lewy Body Dementia 10AM-12:00PM OR 5:30-7:30PM Monday, September 22
- Savvy Caregiver
 12:00PM-2PM
 Wednesdays, 6 week course
 September 24 October 29
 Free, Registration Required
- Art Links
 Fridays, 11AM-Noon
- Mind Matters
 Tuesdays, Screening Required
 10AM-11:30AM

MAT-SU VALLEY

10355 E. Palmer-Wasilla Hwy. 746-3413

ABC's of Caregiving

- The Dementias 10-11:30AM OR 1-2:30PM Tuesday, August 26
- Seniors Need Connections 10-11:30AM OR 6-7:30PM Tuesday, Sept 16
- Savvy Caregiver
 1:00PM-3:00PM, Wednesdays
 Sept. 17 Oct. 29
 Free / Registration Required
- Art Links 1-2 PM Every Friday
- Mind Matters

 10:30AM NOON

 Wednesdays, Screening Required

FAIRBANKS

565 University Dr., Suite 2 452-2277

- Art Links
 Thursdays, 1:30-2:30PM
- Filling the Day with Meaning I 5:30-7PM Tuesday, August 12
- Filling the Day with Meaning II 5:30-7PM Tuesday, August 19
- Our Aging Selves
 Myths and
 Realities of Aging
 5:30-7PM
 Tuesday, September 16
- Savvy Caregiver
 5:30-7:30PM
 Thursdays, September 11 and October 16

JUNEAU

3225 Hospital Dr., 1st Floor Conference Rm 586-6044

- Complaints of a Dutiful Daughter 12-1:30PM Wednesday, August 27
- Honoring Connection: Communication Tips for Caregivers Tuesday 5:30 - 7PM September 30
- Art Links is Coming to the Juneau Office in September!
 Contact Amber for more info
- Savvy Caregiver Workshop October/November Contact Amber if interested

COPPER RIVER BASIN

822-5620 Glenallen Senior Center

Brain Fitness
"Senior Scribblers" Time TBA
2nd Wednesday & Last Thursday
Starting 7/19

PROFESSIONAL WEBINARS

Free / Registration Required email Amber at asmith@alzalaska.org

- Storytelling and Reminiscence: 12-1PM Tuesday, July 22
- Creativity and Dementia: 12-1PM Tuesday, August 26
- The Dementias: Knowing the Dementias Makes a Difference: 12-1PM Tuesday, September 30

FAMILY CAREGIVERS WEBINARS

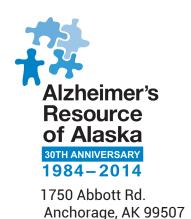
Free / Registration Required
email Gay at gwellman@alzalaska.org
Thursdays from 7 - 8:30PM

- End of Life: Helping with Comfort and Care August 14
- Introduction to Dementia / Alzheimer's Disease
 September 11
- Understanding Adult Guardianship
 October 9
- Behaviours That Challenge Us November 6
- Holiday Connections;
 The Holidays and Dementia
 December 11

ON-LINE SAVVY CAREGIVER for FAMILIES
Free, Registration Required
Wednesdays - October 1, 8, 15, 22, 29 and November 5
Email Gay at gwellman@alzalaska.org



| Anchorage | and mends of persons | with dementia to share ex | Refrences and sor | utions. | | |
|--|----------------------|---|-------------------|---|--|--|
| Alzheimer's Resource of Alaska | General Caregiver | 2nd Thursday | 12PM-1:30PM | Debbie Chulick | | |
| 1750 Abbott Rd. | General Caregiver | 4th Thursday | 5:30-7 PM | 561-3313 | | |
| Chester Park Cooperative 2020 Muldoon Rd. | General Caregiver | 1st Friday | 10 -11:30 AM | Kim Jung 561-3313 | | |
| Eagle River | | | | | | |
| Holy Spirit Episcopal Church 17545 N. Eagle River Loop Rd. | General Caregiver | 2nd Thursday | 6:30-8 PM | Marilyn McKay 561-3313/Linda Shepard 746-3413 | | |
| Statewide Telephone Support Group | | | | | | |
| Alzheimer's Resource of Alaska | General Caregiver | 1st and 3rd Wednesda Dial in 1-877-216-155 | • | Gay Wellman 882-5620 or (800) 478-1080 x6 | | |
| Fairbanks | | | | | | |
| Alzheimer's Resource of Alaska 565 University Ave. Suite 2 | General Caregiver | 1st & 3rd Tuesday | 11:30AM-1PM | Joan Adams 452-2277 | | |
| Homer | | | | | | |
| Friendship Center | General Caregiver | 2 Thursday's a month | 2:30-3:30 | Mary Jo 235-2295 | | |
| Juneau | | | | | | |
| Bridge Adult Day Center 1803 Glacier Highway | Family Caregiver | Thursdays | 6:30-8 PM | Joylynn for INFO at 463-6177 or 866.746.6177 | | |
| Ketchikan | | | | | | |
| Southeast Senior Services | Family Caregiver | Call for more information | | Bernice 225-8080 | | |
| Kodiak | | | | | | |
| Kodiak Senior Center 302 Erskine Ave. | General Caregiver | 4th Thursday | 12:30-1:30 PM | 486-6181 | | |
| Mat-Su Valley | | | | | | |
| Alzheimer's Resource of Alaska Trinity Barn Plaza Mile 2.2 Palmer-Wasilla Hwy. | General Caregiver | 2nd Wednesday | 1-2:30 PM | Linda Shepard 746-3413 | | |
| Seward | | | | | | |
| Seward Senior Center | General Caregiver | 4th Thursday | 1-2 PM | 262-1280 or (800) 776-8210 | | |
| Sitka | | | | | | |
| Brave Heart Volunteers | General Caregiver | 2nd Wednesday | 12-1 PM | 747-4600 | | |
| Soldotna | | | | | | |
| Soldotna Senior Center | General Caregiver | 2nd & Last Tuesday | 1-3 PM | 262-1280 or (800) 776-8210 | | |
| Sterling | | | | | | |
| Sterling Senior Center | General Caregiver | 1st Tuesday | 1-2 PM | 262-6808 | | |



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- •For more information, please visit www.fredmeyer.com/communityrewards.

