

## Kako'o: The Aloha Chapter Newsletter

Published quarterly for our donors, volunteers, advocates and friends in the Alzheimer's community

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# Kako'o

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## 25 years of serving Hawai'i's families...

*A Message From Janet Eli  
Alzheimer's Association – Aloha Chapter  
President & CEO*

This year, the Alzheimer's Association – Aloha Chapter celebrates a major milestone in Hawai'i—25 years of providing help and hope to individuals affected by Alzheimer's disease, their families and caregivers and working toward fulfilling our mission of eliminating the disease through research. When the Association had its humble beginnings in Hawai'i in 1982, Alzheimer's disease was rarely diagnosed, and no treatments or services were available.

Our founders were determined to change the way people think about Alzheimer's disease. Their commitment sparked a generation of unprecedented progress as the Alzheimer's Association assumed an ever-growing role as the catalyst and leader in Alzheimer research and care.

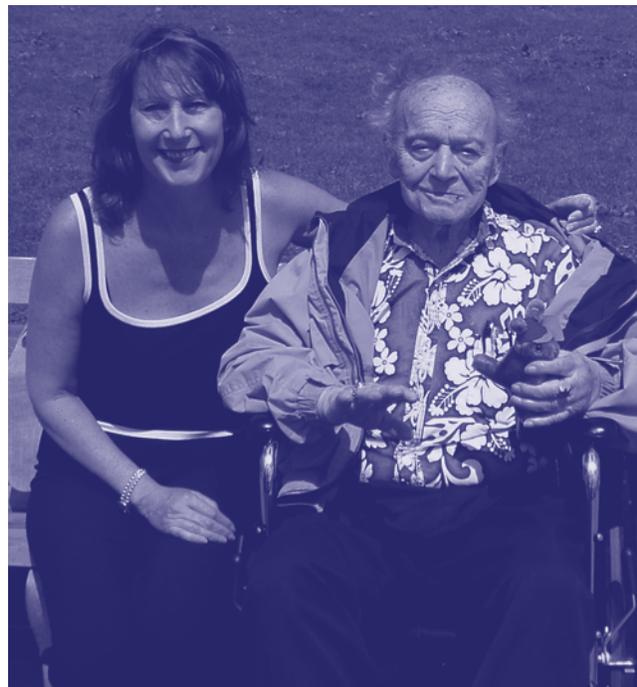
Thanks to the courage, foresight

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## Alzheimer's: My Father's Song

*by Lillian Koller, Director, Hawai'i State  
Department of Human Services  
Alzheimer's Memory Walk 2006 Statewide  
Honorary Chair*

By the time I got there, he was contorting his frail body as violently as his 92 years could muster, gripping the rails of the hospital bed, twisting, kicking, hurling and exhausting himself, crying out tortured nonsense:



*Lillian Koller and her father, David Mayer Koller (1912 – 2005), a few days before his death.*

“The circle, the circle, can't get out, the circle, we're all dead in the circle, going down, down, down, the circle, can't stop, the circle, look, look, help me, the circle, the circle...”

I had no idea what my Father meant. My Father—who had always been my beacon of wisdom and strength—was a Polish Jew, numbers branded on his arm. Everyone in his family, everyone he knew and loved,

was murdered in the Holocaust. He must be trying to tell me something now, as he had always done before. My mind flashed on all the times I sat by my Father's side, fearful but entranced by his stories of what it was like to witness unspeakable horrors and live to tell about them. He had the indomitable spirit and the guilt of the survivor. He found meaning in it

all, under the worst of circumstances. He found love, he made a family and he had a reason to live.

There must be meaning in my Father's words now, as he thrashed in bed restraints ranting about “the circle.” I stood with my stepmother and my brother, watching my Father in disbelief. “It must be a stroke,” one of us insisted. Anything seemed better than the thought that my Father had an incurable, degenerative brain disease.

Alzheimer's had manifested suddenly for my Father. He lost rationality seemingly all at once.

“Dad, it's me, I'm here, I love you. There's no circle, Dad. Please calm down. Your heart can't take this.” As we did not understand him, he did not understand us. His anguish heightened as he continued to plead with us, entreat us to listen and understand him, begging us to see the circle as he saw it, comprehend the circle, the madness that had seized him and

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## Alzheimer's: My Father's Song

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wouldn't let go.

By evening, my Father resigned himself to shut us all out. He was angry with us, I guess, or just hopeless. We couldn't soothe him. So he fell silent. For days, he kept his eyes shut. He did not speak, he did not eat, he did not react. He was breathing low and slow, as if he could choose to die like this, or punish us for not understanding him. I had planted myself by his side, stroking his hand. No response. Speaking words of love softly to him. No response. Weeping. No response.

Then, more to comfort myself than him, I began softly singing a Yiddish lullaby he used to sing to me as a child. My memory of the song was

shaky. The language of the song was foreign and I'm sure I mangled the words. But the melody I remembered clearly, and it was sweet to me. So I sang it, over and over, quietly so nobody in the hospital could hear me.

Suddenly, his eyes still shut, my Father gently lifted his right hand and forearm and began moving them slowly up and down in rhythm as I sang. Soon he began to sing with me, eyes still closed, singing with more and more clarity, articulating the foreign lyrics better than me, weaving his singing with mine, louder and louder. The steady rhythm, the sweet melody, the simple song.

After what seemed like an eternity of time suspended, my Father opened his eyes. He squeezed my hand and

smiled appreciatively. "We broke the circle," he said, looking deeply in my eyes, "We broke the circle." ●

*The Alzheimer's Association – Aloha Chapter, offers assistance to Alzheimer's patients, families and caregivers in Hawai'i statewide. Call 591-2771. To learn more about Alzheimer's disease or to get help on Maui, call Elaine Slavinsky, program coordinator, at (808) 242-8636 or visit [www.alzhi.org](http://www.alzhi.org).*

## 25 years of serving Hawai'i's families...

(Continued from page 1.)

and leadership of a cadre of dedicated volunteers representing the professional and lay community, Hawai'i's families and friends of loved ones with the disease formed pockets of understanding and support, championed the increase of services and community resources, spearheaded campaigns for community awareness and campaigned at the national level for increased funding for effective treatments and to eliminate the disease.

In the past 15 years, we have discovered 95 percent of what we know about the disease. We now anticipate breakthroughs within the coming years that will enable us to intervene in the disease process to limit its disabling effects—and the Alzheimer's Association is leading the movement to make brain health a national priority.

The Alzheimer's Association continues to increase its impact on people's lives through our:

- Coast to coast network of 81 chapters and more than 300 points of service, including support on all Neighbor Islands;

- A Nationwide Contact Center Helpline, which offers 24/7 information, referral and care consultation in 140 languages;
- Website, [www.alzhi.org](http://www.alzhi.org), providing resources at the local and national levels;

*A friend hears the song in my heart and sings to me when my memory fails.*

—Anonymous

- Safe Return™ program, which has registered individuals in Hawai'i and facilitated the return of hundreds of those who have wandered over the years;
- Education and specialized training programs; and
- Advocacy for greater public funding for research.

Your support has been a vital part of these achievements, and we thank you as we build toward our vision of a world without Alzheimer's disease. ●

*Aloha pumehana,  
Janet Eli*

## Brain Facts

- The brain stops growing at age 18.
- The human brain is the body's most powerful organ, yet weighs only about 3 pounds.
- The human brain is approximately 75 percent water.
- An adult brain contains about 100 billion nerve cells, or neurons, with branches that connect at more than 100 trillion points.
- With each heartbeat, arteries carry about 20 to 25 percent of the body's blood to the brain, which uses about 20 percent of the oxygen and fuel the blood carries. When you are thinking hard, the brain may use up to 50 percent of the oxygen and fuel.
- The brain of a person with advanced Alzheimer's disease is dramatically smaller than a healthy brain because so many brain cells have died.

**You never know** when you might need to reach us. Now you know you always can—24-hours a day, 7 days a week.

**The Alzheimer's Association  
Contact Center**

**1-800-272-3900**

## Finding a Safe Return® at the Alzheimer's Association

The Alzheimer's Association's Safe Return® is a nationwide identification, support and enrollment program that provides assistance when a person with Alzheimer's or a related dementia wanders and becomes lost locally or far from home. Assistance is available 24 hours a day, 365 days a year. If an enrollee is missing, one call immediately activates a community support network to help reunite the lost person with his or her caregiver.



Safe Return® faxes the enrolled person's information and photo (if provided) to local law enforcement. When the person is found, a citizen or law enforcement official calls the 800 number on the identification products and Safe Return® notifies listed contacts. The nearest Alzheimer's Association office provides information and support during search and rescue efforts.

### Safe Return® ID products

You will receive the following items with your \$40 enrollment:

- Engraved identification bracelet or necklace and iron-on clothing labels.
- "Five steps for a Safe Return" magnet card, key chain, lapel pin, telephone stickers and wallet cards.

Caregiver jewelry is available for an additional \$15. In an emergency, it alerts others that you provide care for a person with dementia.

### Enroll in Safe Return®

Enrolling a person with dementia in Safe Return is easy. A caregiver fills out a simple form, supplies a photograph (if available), chooses the type of

## CareFinder™ Helps Locate Best Care Options

Millions of people affected by Alzheimer's disease find it a challenge to find good care for themselves or their loved ones. The Alzheimer's Association's new CareFinder™ helps users find options ranging from home and community-based care to assisted living and nursing home care.

Just enter personalized information at [www.alz.org/carefinder](http://www.alz.org/carefinder) on your needs and preferences and CareFinder™ will give you care recommendations and questions to ask care providers. CareFinder™ also offers information on many issues related to care options, including:

- **Planning Ahead.** A person in the early stages of Alzheimer's may still be able to make decisions, so it is important that the individual participate as much as possible in discussions about future care, legal and financial planning.
- **Care Options.** CareFinder™ defines and outlines the many types of care available to meet the unique needs of individuals with dementia so

families can determine what care is needed for their loved ones.

- **Coordinating Care.** A person with Alzheimer's may receive care from several types of providers, from physicians to in-home assistance to long-term care, such as assisted living and nursing homes. CareFinder™ offers advice to keep families engaged in the care of their loved ones, communicate with doctors and other care providers and addresses changing needs, such as moving a loved one to a long-term care residence.
- **Support and Resources.** The Alzheimer's Association Helpline (1-800-272-3900) is available 24/7 to help anyone affected by Alzheimer's disease. CareFinder™ also offers information about other support programs for people with Alzheimer's and their caregivers, including web links to resources such as the Eldercare Locator and National Academy of Elder Law Attorneys (NAELA). ●

identification product that the enrollee will wear and/or carry and pays the \$40 enrollment fee. After the first year of enrollment, the annual program administrative fee is just \$20. You will receive an invoice requesting the \$20 fee toward the end of the first year. This helps Safe Return respond to more than 6,000 calls for help each year.

There are three ways you can enroll:

- 1) **Online:** Visit [www.alz.org](http://www.alz.org). Enroll with our secure form. It's fast and easy.
- 2) **Phone:** Enroll by phone using a credit card. Call 1-888-572-8566 between 7:00 am - 11:30 pm (CST). Representatives are available Monday through Friday.
- 3) **Mail:** To enroll by mail, complete the enrollment form and send payment and enrollee photo to: P.O. Box A3687, Chicago, IL 60690-3687. You may also phone 1-888-572-8566 to have an enrollment form mailed to you.

When enrolling online or by phone, you will be asked to provide the following information:

- Enrollees' name and contact information.
- Enrollee's identifying characteristics (height, weight, eye color, distinguishing marks and characteristics, etc.).
- Enrollee's exact wrist measurement in inches (required when ordering a bracelet).
- At least two contact names, addresses and phone numbers (more can be added, if needed).
- Local law enforcement phone number.
- Credit card number and expiration date.

### Wandering: Who's at Risk?

Call Safe Return® today if you know someone who:

- Returns from a regular walk or drive later than usual.

(Continued on page 5.)

## Memory Walk 2006: Aloha Chapter Raises \$104,953



Honolulu, September 9

**Total Raised:** \$46,779

**Top Team:** Nuuanu Congregational Church, \$4,939

**Most Participants:**

The Plaza at Punchbowl, 84 walkers

**Top Individual:** Arlene Kim, \$1,775



Hilo, September 30

**Total Raised:** \$14,968

**Top Team:** HMSA Hilo, \$1,325

**Most Participants:**

Curves of Hilo, 50 walkers

**Top Individual:**

Carol Van Camp, \$520

Kaua'i, October 7

**Total raised:** \$4,148

**Top Team:** Wilcox Hospital, \$1,275

**Most Participants:**

Regency at Puakea, 8

**Top Individual:** Janice Bond, \$245



### 5K Run Results

**Top Male Runner:**

Jonathan Lyau, 16:17

**Top Female Runner:**

Mina Casey-Pang, 21:01

**Top Male Runner, Military:**

Brent Bishop, 20:14

**Top Female Runner, Military:**

Jamie Seluk, 32:41



Maui, October 14

**Total Raised:** \$27,053

**Top Corporate Sponsor:**

The Dowling Company, \$10,000

**Top Team:** Solid, \$1,043

**Most Participants:**

Maui Credit Union, 37

**Top Individual:**

Colleen Fujimoto, \$630



*Above: (l to r) Elaine Slavinsky, Program Coordinator, Maui County Office; Candi Aluli, Vice Chair, Board of Directors, Everett Dowling and Susan Lincoln, Resource Coordinator, Maui County Office.*



Kona, October 28

**Total Raised:**

\$12,005

**Top Team:** Life

Care Center of Kona, \$1,420

**Most Participants:**

Kona Police Department, 23

**Top Individual:**

Josephine Fergerstrom, \$753



## Moonlight & Memories 2007: Some Enchanted Evening

The Alzheimer's Association – Aloha Chapter Celebrates its 18th Annual Moonlight & Memories for 2007.

We invite you to join us in commemoration of our 25th year anniversary at the Alzheimer's Association Moonlight & Memories 2007--Some Enchanted Evening--on Saturday, March 31, 2007 at the Hilton Hawaiian Village Tapa Ballroom. The

evening will include a delectable dinner, fabulous entertainment, a unique silent auction and fun with a 1940's South Pacific theme.

**Hilton Hawaiian Village  
Tapa Ballroom  
Saturday, March 31, 2007  
5:30 – 11:00 pm**

### Table Reservations:

Enchanted Evening Table - \$5,000  
Bali Hai Table - \$3,500  
South Pacific Table - \$2,500  
Younger Than Springtime - \$1,500  
Individual Tickets - \$150

To reserve your table or seat, or to donate to the Silent Auction, please call Mr. Dave Hamil at 591-2771.



### Alzheimer's Workshop: What Now?

Alzheimer's disease can strike people under the age of 50 but most commonly occurs with those over 65. The effects of this disease can have an enormous impact on the families and friends of the diagnosed person, as well as on the community at large. As more people move through the aging process in Hawai'i, the incidence of Alzheimer's disease is expected to triple over the next 30 to 40 years. The WHAT NOW? Workshop and accompanying easy-to-use manual was developed especially for busy caregivers and family members. The orientation and manual are free to family caregivers.

Topics include: a comprehensive guide to understanding the specifics of the disease; how to begin with the medical, legal and financial issues; how to approach some of the more challenging care situations that arise; introductions to homecare planning and management; steps to take when exploring residential facilities; and navigating the waters for family relationships.

If you are caring for someone with Alzheimer's disease or a related dementia, you won't want to miss this presentation. To register and for location call:

**Hilo, Hawai'i:** 981-2111

**O'ahu Chapter Office:** 591-2771

**Lihue, Kaua'i:** 245-3200

**Maui Program Office:** 242-8636

### WORKSHOPS AND PRESENTATIONS

#### *SAGE PLUS Medicare Overview*

Saturday, February 10

10:00 am - 11:30 am

Ward Warehouse

Kaka'ako Conference Room

Call 591-2771 to register

#### *Maintain Your Brain™*

Saturday, February 10

1:30 pm - 2:30 pm

Ward Warehouse

Kaka'ako Conference Room

Call 591-2771 to register

#### *Understanding Memory Loss*

10:00 - 11:00 am

#### *Maintain Your Brain*

12:00 - 1:00 pm

#### *Care Planning*

10:00 am - 3:00 pm by appointment only

Saturday, February 17

Lihue Neighborhood Center

Call 245-3200 to register

#### *Maintain Your Brain™ Brown Bag*

Lunch Presentation

Wednesday, February 21

11:30 am - 12:30 pm

Maui Office

Call 242-8636 to register

#### *Normal Aging vs. Memory Loss*

Brown Bag Lunch Presentation

Wednesday, March 14

11:30 am - 12:30 pm

Maui Office

Call 242-8636 to register

### SUPPORT GROUPS

Support Groups provide caregivers and care partners the opportunity to share information and learn from one another in a supportive and caring environment. Please call the Alzheimer's Association – Aloha Chapter for the location of a support group near you. O'ahu: 591-2771; Maui: 242-8636; Big Island: 981-2111; Kaua'i: 245-3200.

## Finding a Safe Return®

(Continued from page 3.)

- Tries to fulfill former obligations, such as going to work.
- Tries or wants to "go home" when already at home.
- Is restless, paces or makes repetitive movements.
- Has difficulty locating familiar places such as the bathroom, bedroom or kitchen.
- Checks the whereabouts of familiar people.
- Performs a hobby or chore but accomplishes nothing (for example, moves around pots and dirt without planting anything).
- Appears lost in a new or changed environment.

For more information, call the Alzheimer's Association at 1-888-572-8566 or visit [www.alz.org/safereturn](http://www.alz.org/safereturn). ●

## Passionate Volunteers Needed

### Volunteer Opportunities

Volunteers are the heart of our Aloha Chapter. If you are looking for a way to make a difference for the families and caregivers living with Alzheimer's disease, join our Volunteer Team at the Alzheimer's Association - Aloha Chapter! For more information on the volunteer opportunities outlined below, please call the Aloha Chapter office at 591-2771.

### Speaker's Bureau

Be the voice of the Alzheimer's Association. Make presentations and provide information regarding the issues concerning Alzheimer's disease and the services offered by the Alzheimer's Association to the community. You will attend a training session and become familiar with literature and videos available at the Alzheimer's office. Days and hours are varied. One year commitment.

### Support Group Facilitators

Lead a monthly support group for family, friends and professional caregivers of individuals with dementia. The meetings provide a safe environment where people can share ideas, experiences, information and coping skills. Must be able to listen in a kind



and non-judgmental manner and tactfully ensure each group member has an opportunity to share during meetings. Health related degree required. Prior experience in counseling a plus. You will attend training sessions throughout the year and facilitate one support group session per month for approximately two hours. The commitment is for one year.

### Memory Walk/5K Run Committee Leadership

The Memory Walk is the single largest fundraiser for the Alzheimer's Association nationwide, with over 600 communities participating throughout the United States! Provide leadership for Committee meetings and Committee responsibilities. Attend Steering Committee meetings. Serve as a



Chair/Co-Chair for one of the following committees:

- Communications/Graphics
- Corporate Sponsorship
- Food and Entertainment
- Health/Information Fair
- Homebase Logistics
- Prizes
- Publicity
- Route Logistics
- Team Captains
- Team Recruitment
- Volunteer
- Videography

## Enhance your home for an Alzheimer's patient

- Lock up cleaning supplies.
- Turn off electricity to the garbage disposal.
- Hide knives and other utensils.
- Put away the toaster, blender and any small appliances.
- Unplug larger appliances.
- Remove knobs from stove or hook up stove to a hidden gas valve or electric switch.
- Keep fire extinguisher nearby.
- Clean out refrigerator.
- Set water temperature at 120.°



- Install grab bars in bathroom.
- Apply textured decals on slippery surfaces.
- Supervise the use of hairdryers, electric and hand razors and curling irons.
- Remove locks from bathroom doors.
- Discard dangerous items from the medicine cabinet. ●

### Health Fair & Information Table Volunteer

Serve the community at island-wide health fairs and information booths. Encourage people to learn more about Alzheimer's disease and the services available at the Alzheimer's Association. Transport items to and from locations for display, arrange materials on table and distribute fliers. Assemble and disassemble health fair information tables. Approximately four hours per week. One year commitment. ●

## FDA Increases Commitment to Fight Alzheimer's Disease



Recognizing the urgent need to address Alzheimer's, the U.S. Food and Drug Administration (FDA) is increasing its commitment to fighting

the disease. As a result of meetings with the Alzheimer's Association, the FDA has established an Intra-Agency Neurology Working Group of experts to better address technical and regulatory issues in diagnosing and treating Alzheimer's and other neurological diseases. In addition, acting on

the Association's recommendation, the FDA will expand its existing Patient Consultant program to include caregivers and people with Alzheimer's in the drug review process.

The Association continues its advocacy efforts to ensure safe and effective treatments are available as quickly as possible. This includes broadening public participation in drug clinical trials to speed research on treatments; advocating for increased federal funding so the FDA can better respond to rising demands for drug reviews; and creating an Association-funded Alzheimer's neuroscience fellowship at the FDA to help expand the agency's critical expertise on Alzheimer treatments. ●

## The \$248,000,000,000 Dollar Question

The worldwide cost of Alzheimer's disease and dementia care is \$248 billion, reported researchers from the Stockholm Gerontology Research Center and Aging Research Center at Karolinska Institutet, Sweden. The figure includes both direct (formal) and informal care costs. Informal care is provided without cost, usually by family members and friends. Direct (or formal) care costs generally include professional healthcare services, including treatment, housing and ongoing daily care, for which fees are assessed. This study estimated informal costs by examining existing published data for unpaid care and average wage levels in various countries.

"These startling cost estimates for Alzheimer's care clearly illustrate the great challenges faced both by families and our national healthcare systems as the number of people with Alzheimer's continues to grow," said William Thies, PhD, Alzheimer's Association vice president of medical and scientific relations. "Increasing the funding for Alzheimer's research into early detection, better treatment and



prevention is critical to curbing this impending world health disaster. We can fund research now or wait for Alzheimer's to overwhelm the health systems in the U.S. and throughout the world."

The researchers previously estimated the worldwide direct cost of dementia at \$156 billion, adding a newly determined figure of \$92 billion for informal care costs to total \$248 billion. ●

# DRIVEN Membership

*Membership Means Commitment*

Official 2007  
Membership  
Form. Please cut  
out or photocopy  
and mail to the  
address below.

YES, I would like to make a commitment to the Alzheimer's Association–Aloha Chapter.

New Member     Membership Renewal

Name \_\_\_\_\_ Company Name \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip \_\_\_\_\_ Phone \_\_\_\_\_

Register me in the following category:  Contributing \$30     Participating \$75     Sustaining \$150  
 Benefactor \$500     Patron \$1,000     Other

I want my membership to support services in:  O'ahu     Maui     Hawai'i     Kaua'i     Other

Please make checks payable to Alzheimer's Association–Aloha Chapter or charge my credit card:

MC     Visa     AMEX    Card no.: \_\_\_\_\_    Expiration date: \_\_\_\_\_

Please cut out this Membership Form and mail to:

Alzheimer's Association–Aloha Chapter; 1050 Ala Moana Blvd., Bldg. D-15; Honolulu, Hawai'i 96814-4924

Aloha United Way



Another Way to Give...

www.alzhi.org  
1-800-272-3900

We are fighting on your behalf 24/7  
to give everyone a reason to hope.

Alzheimer's Association - Aloha Chapter  
1050 Ala Moana Boulevard, Bldg. D-15  
Honolulu, Hawai'i 96814-4924

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