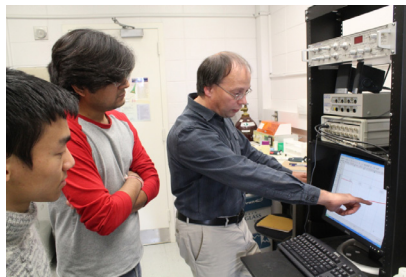


Newly Discovered Disease Could Hold Key to Alzheimer's, Parkinson's – and even aging



A new genetic disease has been discovered that could play a key role in devastating brain conditions such as Alzheimer's and Parkinson's, opening up the possibility of new forms of treatment.

A 47-year-old Canadian woman, who had been having difficulty walking and balancing since she was 28, was found to have a new genetic disease after 10 known conditions were ruled out, according to a paper in the journal *Nature* by an international team of researchers.

The disease causes an over-reaction by the body's natural repair system. An enzyme, known as PARP1, goes into over-drive, ultimately causing the deaths of brain cells. It is believed this process could also be involved in the death of cells in other forms of dementia and possibly even the aging process.

Professor Keith Caldecott, of

Sussex University, who led the research, said: "Discovering this new disease and its cause is a huge step towards developing drug-based therapies for other rare neurodegenerative conditions.

"Drugs which target this key DNA-repairing enzyme in the right way could prove vital for treating people suffering from diseases caused by the over-activation [of the enzyme]. It is now crucial we determine what diseases these are.

"More research needs to be done, but it's also possible the cause of this newly discovered condition could contribute to the death of nerve cells in people suffering from diseases such as Alzheimer's, Huntington's and Parkinson's."

In experiments, the researchers were able to shut down the out-of-control repair process, which they likened to a flashing light that runs down the cell's batteries, using genetic techniques. Even though the DNA was still damaged, the cells did not die.

Professor Caldecott told the *Independent* that the link to other

(Cont.) Page 4

Helping Children Understand Alzheimer's Disease

When a family member has Alzheimer's disease, it affects everyone in the family, including children and grandchildren. Giving children understandable information about Alzheimer's can help them cope with the disease in their family. The type of relationship the child has with the family member and the child's age are important to help determine:

- What information the child receives
- How the information is presented
- The child's part, if any, in caring for the person with Alzheimer's disease

It is important to answer children's questions simply and honestly. For example, you might tell a young child, "Grandma has an illness that makes it hard for her to remember things."

You can help children know that their feelings of sadness and anger are normal. Comfort them. If children express guilt or feel that they may have done something to hurt their

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Fax 561-3315

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Phone (907) 452-2277
Fax 457-3376

Juneau

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Fax 586-6084

www.AlzAlaska.org

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Hwy.
Suite 110
Palmer, AK 99645
Phone (907) 746-3413
Fax 746-3412

Copper River Basin

(907) 822-5620

Statewide

Toll Free within Alaska
(800) 478-1080





Letter From The Executive Director

Greetings,

At Alzheimer's Resource of Alaska, we measure success by our ability to ensure the highest quality of life for our most vulnerable community members. In relying on the support of Alaskans throughout the state we are able to amplify that support and make certain that those in need know that they are not alone.

This year's Amblin' for Alzheimer's event was a great success and raised more than fifty-thousand dollars for Alaskans throughout the state who are living daily with Alzheimer's Disease and related dementias (ADRD). The number of individuals who joined us while taking a stroll along the Anchorage Golf Course is a clear testament to the dedication and commitment we all share for our fellow Alaskans in need.



In this newsletter, we have several articles on research and the vital role it plays in helping solve the Alzheimer's puzzle. We are grateful for the increased research that may lead to new Alzheimer's therapies. We will continue to share new information as it becomes available.

As we strive to meet the needs of the community, we are adding services that will have an impact on communities across the state. Recently, our Education Director, Pam Kelley traveled to Western Alaska where she spent several days analyzing care practices using Dementia Care Mapping (DCM™), an innovative tool that can assist places like nursing homes and assisted living facilities in their efforts to increase quality care. Visit page 7, to learn more about DCM™.

Alzheimer's Resource of Alaska reached the end of another fiscal year on June 30, and as I review the past 12 months, I find myself once again proud to be part of our organization and inspired by the work our staff accomplishes throughout Alaska with your help. We can add innovative programs and expand services as a result of the funding we receive from you, our partners. I thank you for your commitment to our programs and services and look forward to continuing to ensure the quality of life of those we serve in the year ahead.

Best Regards,

Executive Director

Newly Discovered Disease Could Hold Key

(Continued from page 1)

diseases and “potentially even normal ageing” was “speculative”.

But he said they were now beginning the search for drugs that could achieve the same thing as the genetic techniques used in the lab, but could also be given as a treatment to patients.

When they discovered the new disease, Professor Caldecott said: “It was stunning, really exciting. If we turn that light off, that seems to take away all of the pathology, the cell death. Now what we need to do is turn that light off using drugs instead of genetically.”

There is no treatment for the Canadian woman whose condition is expected to get progressively worse. However, despite her problems with balance and motor skills, she is otherwise healthy. She has been advised to avoid things that cause damage to DNA, such as cigarette smoke, car exhausts and other fossil fuel emissions, X-rays and some forms of cancer treatment should that become necessary.

Dr Doug Brown, director of research and development at the Alzheimer’s Society said: “This research provides an insight into DNA damage and repair in the brain. Researchers found that a change in a gene important for DNA repair led to problems with controlling the body’s movement.”

“However at this stage of research it’s not clear if the findings from this rare condition affecting movement will be relevant for people with dementia. The vast majority of cases of dementia are not inherited. Evidence shows that dementia is caused by a complex interplay of genetics, environmental and lifestyle factors. Further research into each of these factors will help us to better understand why people develop the condition and help us to find effective treatments.”

Source: <http://www.independent.co.uk> Ian Johnston Science Correspondent

Our community comes together to provide support in many forms. Sometimes it is people’s time and talent. Other times it’s gifts of financial and material goods. Our volunteers and in-kind contributors make special contributions that clearly show their dedication to the programs and services of Alzheimer’s Resource of Alaska. Thank you.

Volunteer & In-Kind Donations

The Addonisio Family
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Anchorage Golf Course
Jennifer Badgett
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Sals New York Grill
Upper One Studio’s
Jamie Veal-Scheben
Ashley Werts



Helping Children Understand Alzheimer's Disease *(Continued from page 1)*

grandparent, reassure them that they did not cause the disease.

Do not expect a young child to help care for the person with Alzheimer's disease. Make sure a child of any age has time for his or her own interests and needs, such as playing with friends, going to school activities, or doing homework.

Make sure you spend time with your child, so he or she does not feel that all your attention is on the person with Alzheimer's. Help the child understand your feelings. Be honest about your feelings when you talk with a child, but do not overwhelm him or her.

Many younger children will look to you to see how to act around the person with Alzheimer's. Show children they can still talk with the person, at least in the early stages of the disease. Doing fun things together, with parental supervision depending on the age of the child, can help both the child and the person with Alzheimer's. Here are some things they might do:

- Walk in the neighborhood
- Do simple arts and crafts
- Play music
- Sing
- Look through photo albums
- Read stories out loud

However, in the later stages of disease, the person with Alzheimer's may be completely

unresponsive. This may be very hard for a child to understand. Some children might not talk about their negative feelings, but you may see changes in how they act. Problems at school, with friends, or at home can be signs that they are upset.

You may want to ask a school counselor or a social worker to help a child understand what is happening and how to cope.

A teenager might find it very hard to accept how the person with Alzheimer's disease has changed. He or she might find the changes upsetting and not want to be around the older person. It is a good idea to talk with teenagers about their concerns and feelings. Do not force them to spend time with the person who has Alzheimer's. This could make things worse.

If the stress of living with someone who has Alzheimer's disease becomes too great for a child, talk to other family members or friends about helping out. Or, find out about, and consider using, respite care options available in your community. Then, both you and your child can get a much-needed break.

National Institute on Aging

Take a Webinar

Regardless of your location, you can attend a training offered by Alzheimer's Resource of Alaska's knowledgeable education staff.

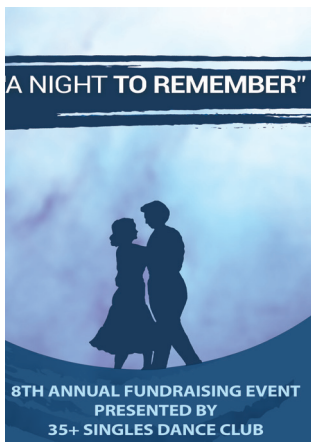
We offer webinars for both the professional and family caregivers giving you the opportunity and flexibility to attend a training that may not be available in your area.

Visit page 10 to see which classes will be offered during July, August and September.

"I took the Savvy Caregiver class and learned so much. I recommend that everyone taking care of someone with dementia take it. Education Specialists are awesome!"



Save THE Date...



A Night To Remember
Date: Saturday, September 9th
Time: 7pm Door Opens
Location: Carpenter's Hall
401 Denali, Anchorage
Additional Information:
Tonda Scott (907) 947-3146
www.alzalaska.org/events

SEPTEMBER!



Stand Up!

Living with Alzheimer's

Comedian: Black Sheep
Date: Saturday, October 7th
Time: 6:30 Door Opens
Location: Willowaw, 601 F Street
To Purchase Tickets Contact:
(907) 561-3313
Silent Auction
www.alzalaska.org/events



For a Cause

Laughing for Life



OCTOBER!

So You Think You Can Give?
12pm, Sunday, November 5 at
Alaska Dance Theatre

Join us for an afternoon of dance for a good cause!

16 classes + a gala performance!

alaskadancetheatre

MOMENTUM
DANCE COLLECTIVE

UNDERGROUND
DANCE COMPANY



NOVEMBER!



Dementia Care Mapping

Long-term care facilities such as nursing homes and assisted living homes face many challenges that make providing quality dementia care difficult. Education, support and training for direct care staff and supervisors are important; however, pinpointing areas that both show the strength and weakness of the daily interactions with residents can be a helpful process.

Dementia Care Mapping (DCM™) is an observational tool designed to capture the experience of care from the perspective of the recipient of care, exploring quality of life as it relates to quality of care. Developed in 1986 by Tom Kitwood, the Dementia Care Mapping (DCM™) method was part of a research project to evaluate quality care in formal dementia settings. This innovative observational tool is being practiced in 24 countries worldwide. DCM™ results, along with the practice of Person-Centered Care, are contributing significantly to today's brighter vision for a life-enhancing social model of dementia care.

A three-step process, one of our four certified staff mappers meets with the relevant staff to introduce the process and how the observation will be carried out. Once the initial meeting is complete, our staff does the observation in common areas such as a living or dining area. The final process is to meet with the management and care staff to share the report and recommendations.

During the mapping, our staff can observe up to five individuals in formal dementia care settings over a four to six hour period. Every five minutes, a Behavior Category Code (BCC), representing what an individual is doing is noted. Simultaneously, Mood and Engagement (ME) values ranging from a -5 to a +5 are assigned. Quality of interactions between staff and recipients of care are also captured, all for the purpose of enhancing the care of the individual care recipient.

This is an open process for all staff: both administrative, supervisory and direct care. Staff members are invited to observe and ask questions anytime and individual staff names are not noted or reported afterwards maintaining their confidentiality. In addition, individual names of the residents observed or the facilities report findings are not shared outside the facility.

After the mapping and report, it is up to management and staff to decide how information will be used. Ideally, findings become part of a facility wide action plan building on present strengths and encouraging systematic improvement in areas of need. DCM™ findings can also increase staff awareness of their own skills and identify specific training needs.

Findings have also been valuable in contributing to participant care plans and evaluating program diversity and effectiveness.

If you would like to schedule a Dementia Care Mapping, contact our Education Director, Pamela Kelley, in Anchorage at 907-561-3313.

Amblin' for Alzheimer's Was a Success

We would like to thank our generous sponsors of the 13th annual Amblin' for Alzheimer's in Kodiak and Anchorage.

Despite the chilly morning, and with your contributions, the event raised more than \$51,000 for our programs and services bringing our 13 years of fundraising to over \$650,000!

We are the only organization in Alaska specializing in Alzheimer's disease, ensuring all of your tax-deductible contributions stay in Alaska, supporting Alaskans!

Alzheimer's Resource of Alaska could not do what it does without the generous commitment of a caring community. Thank you again for your thoughtful support of *Amblin' for Alzheimer's*.

For a list of our contributors visit our page 8.

Individual & Business Contributors

These contributions recieved between April 1 - June 30

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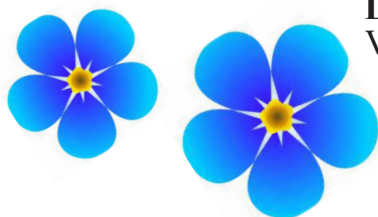
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Gene Williamson



*"I dont know how we could have managed without our
care coordinator, she is there for my dad. I do not know
how we could have taken care of all of his
needs without her." E.S.*

Classes & Events around the state

ANCHORAGE

1750 Abbott Road
561-331

ADRD: Early Stages

Jane Haiar
Monday, 9/11
10-11:30am or 5:30-7pm

ADRD: Middle Stages

Kim Jung
Monday, 9/18
10-11:30am or 5:30-7pm

ADRD: Late Stages

Debbie Chulick
Monday, 9/25
10-11:30am or 5:30-7pm

Savvy Caregiver

Wednesdays, 8/2 to 9/6
2-4 pm
Registration is required

Mind Matters I *

Wednesdays, 7/12 to 8/30
10 - 11:30am
Wednesdays, 9/20 to 11/8
10- 11:30am

Mind Matters II *

Thursdays, 7/13 to 8/31
10-11:30 am
Thursdays, 9/21 to 11/9
10-11:30am

Virtual Dementia Tour

By Appointment
Monday, 8/7
9-4:30pm

Brain Works *

Tuesdays, 7/11 to 8/29
10-11:30am

Brain Works *

Tuesdays, 9/19 to 11/7
10-11:30am

MAT-SU

10355 Palmer-Wasilla Hwy.
746-3413

ABC Presentations

Medicaid Waiver
Monday, 7/24
1-2:30pm

Activities of Daily Living

Wednesday, 8/23
1-2:30pm or 5:30-7pm

End Stage Alzheimer's

Thursday, 8/24
5:30-7pm (Mat-Su Health
Services 1363 W. Spruce
Ave. Wasilla, AK)

Honoring Connection

Tuesday 9/12
1-2:30pm or 5:30-7pm

Virtual Dementia Tour

By Appointment
Wednesday, 9/27
12:30 - 4:30pm

Mind Matters *

Wednesdays, 8/2 to 9/20
10:30am-noon

Art Links

Fridays - Every Week
1-2pm

JUNEAU

3225 Hospital Dr.
586-6044

ABC Presentations

Movie: Alive Inside
Thursday, 7/27
Noon-1:30pm or 5:30-7pm

Assisted Living Homes

Thursday, 8/24
12-1:30 pm or 5:30-7pm

Making Visits Positive

Thursday, 9/28
12-1:30pm or 5:30-7pm

Savvy Caregiver

Tuesdays, 9/26 to 10/31
5:30-7:30 PM
Registration is required.

Virtual Dementia Tour

By Appointment
Thursdays, 8/10
11-7pm

FAIRBANKS

565 University Ave. #2
452-2277

ABC Presentations

Bathing Without a Battle
Tuesday, 7/18
5:30-7pm

Communication Tips

Tuesday, 8/15
5:30-7 pm

Recreational Activities

Tuesday, 9/19
5:30-7pm

Mind Matters *

Thursday, 8/24 to 10/12
1pm-2:30pm

Art Links

Thursday, - Every Week
11am-noon

Virtual Dementia Tour

By Appointment
Tuesday, 9/12
10am-4pm

Savvy Caregiver

Saturday, TBD
10am - Noon
Registration is required.

Wasilla Neighborhood Memory Café

Neighborhood Memory Café
Wasilla Area Seniors, Inc.
(WASI)

1301 S Century Cir, Wasilla

Tuesday, 7/18

Tuesday, 8/15

Tuesday, 9/19

1:00 pm – 2:30 pm

**Pre-Registration
Required*

Statewide Webinars

Connect with us via GoToMeeting or by Telephone

Registration is required.

FOR PROFESSIONALS

Contact Amber Smith
907-586-6044

Bathing Without the Battle
Tuesday, 7/18
Noon-1pm

Stages of Caregiving:
Supporting Families
through Every Stage
Tuesday, 8/22
Noon-1pm

Meaningful Activities
Tuesday, 9/26
Noon-1pm

SAVVY CAREGIVER WEBINAR

Contact Gay Wellman
907-822-5620
Tuesdays, 9/12 to 10/17
7-9 pm

FOR FAMILY CAREGIVERS

Contact Gay Wellman
907-822-5620

Community Resources
Thursday, 7/13
7-8:30 pm

Medicaid Waiver
Thursday, 8/10
7-8:30 pm

Holiday Connections
Thursday, 9/14
7-8:30 pm

Using Music
Thursday, 10/12
7-8:30 pm



Support Groups around the state

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

Statewide Telephone Support Group

Alzheimer's Resource of Alaska	Caregiver	1st Wednesday 7-8 PM 3rd Wednesday 2-3 PM Dial in 1-877-216-1555, Code 927989	Gay Wellman 822-5620 or (800) 478-1080 x5
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Anchorage

Alzheimer's Resource of Alaska	Caregiver	2nd Thursday	12PM-1:30 PM	Debbie Chulick
1750 Abbott Rd.	Caregiver	4th Thursday	5:30-7:00 PM	561-3313
Chester Park Cooperative	Caregiver	1st & 3rd Friday	10 -11:30 AM	Kim Jung
2020 Muldoon Rd.				561-3313

Eagle River

Holy Spirit Episcopal Church	Caregiver	2nd Thursday	5:00-6:30 PM	Linda Shepard
17545 N. Eagle River Loop Rd.				746-3413

Fairbanks

Alzheimer's Resource of Alaska	Caregiver	1st & 3rd Tuesday	11:30-1:00 PM	Joan Adams
565 University Ave. Suite 2		2nd Tuesday	5:30-7:00 PM	452-2277

Homer

Homer Senior Center	Caregiver	2 & 4th Thursdays	2:30-3:30 PM	235-7655
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Ketchikan

Ketchikan Senior Center	Caregiver	Call for more information		Bernice
Upper Level				225-8080

Kodiak

Kodiak Senior Center	Caregiver	4th Thursday	12:30-1:30 PM	486-6181
302 Erskine Ave.				

Mat-Su Valley

Alzheimer's Resource of Alaska	Caregiver	2nd Wednesday	1-2:30 PM	Linda Shepard
<u>10355 E. Palmer-Wasilla Hwy.</u>				746-3413
AK Veterans & Pioneer Home	Caregiver	First Friday	10:00-11:30 AM	Janice Downing
				746-3413

Seward

Seward Senior Center	Caregiver	4th Thursday	1-2 PM	224-5604
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Sitka

Brave Heart Volunteers	Caregiver	Call for more info.		747-4600
120 Katlian Street				

Soldotna

Soldotna Senior Center	Caregiver	2nd & Last Tuesday	1-3 PM	262-1280 or (800) 776-8210
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Leaving a bequest for future generations

If you share our commitment to assist all who turn to us for help, then please consider leaving a legacy to Alzheimer's Resource of Alaska. Your contribution will secure a brighter future for those individuals with Alzheimer's disease and other forms of dementia and their caregivers by sustaining our programs and services such as Care Coordination, Education, Family Consultations and Support Groups.

How to Leave a Legacy

- You can define a specific dollar amount or specify a percentage of your overall estate.
- You can leave the residual amount of your estate after all other specific bequests and obligations are met.
- You can leave a particular asset such as securities, real estate, retirement account or valuable personal property.
- You can leave a portion or all of a life insurance policy or purchase a new policy naming Alzheimer's Resource of Alaska as the beneficiary.

If you are thinking of leaving a legacy gift to the Alzheimer's Resource of Alaska, or if you have already made a commitment to do so, please let us know so we may better serve you and honor your wishes. Contact our development office in Anchorage to discuss what options are available for your bequest.