

# WHEN DISABILITY MEETS ALZHEIMER'S

UCI WILL STUDY THE LINK BETWEEN THE BRAIN DISEASE AND DOWN SYNDROME.

When Ruth Russi was born with Down syndrome in 1959, her parents were told she would die before her fifth birthday. By the time Ruth turned 50, John and June Russi of Costa Mesa began to prepare for her outliving them.

But as she aged, Ruth's behavior changed. She would stare at her crayons, unable to color, or walk out of church still clutching a dollar bill for the offering.

John, 85, and June, 79, were devastated to learn that Alzheimer's disease, a condition they worried about for themselves, had inhabited their daughter's brain. Ruth died last fall, a week before her 56th birthday.

"We'd always been able to make her happy one way or another," John Russi said. "At the end we couldn't make her happy. That hurt."

Those with Down syndrome are not only more susceptible to Alzheimer's, they often experience onset younger. Longer lifespans are creating caregiving burdens for families like the Russis and driving more research into the genetic connection between the developmental disorder and degenerative brain disease.



COURTNEY PERKES  
STAFF WRITER



COURTESY OF JOHN AND JUNE RUSSI

Down syndrome and Alzheimer's patient Ruth Russi, right, of Costa Mesa, died at age 55. With her is her father, John.

## Incidence of Alzheimer's

A 45-year-old adult with Down syndrome has a 20 percent to 25 percent risk of developing Alzheimer's disease. At age 55, the risk is 50 percent. By age 65, the risk is 75 percent.

In the general population, the risk of developing Alzheimer's doubles every five years after age 65. By age 85, the risk is nearly 50 percent.

Source: UCI, Alzheimer's Association

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## FRUMPY MIDDLE-AGED MOM



MARLA JO FISHER  
STAFF COLUMNIST

## I'll stop putting stuff off tomorrow

I've been thinking lately about things I hate to do, but I feel better once they're done.

The subject crossed my mind because I just had my teeth cleaned, which I'd been dreading so much that I made up reasons why I had to postpone the appointment twice.

"Gee, there was an avalanche on Mount Everest, guess I'd better not go to the dentist today" sounded like a perfectly good excuse at the time, though later it occurred to me that others might find it lame.

Then there was the rare and unexpected urge to clean house that came over me shortly before the second appointment, making it impossible to go because I was covered with dust and oven cleaner.

Of course, after I finally did make it to my appointment, which was only as grueling and stressful as breaking down on the freeway during rush hour, I felt smug and self-satisfied.

I kept running my tongue over my newly shiny teeth, and wondering why more people don't get their teeth cleaned, all the time.

Then I came home to my impossibly cluttered house and ignored the mess.

At least once a decade, I feel the biological urge to declutter my house, and start attacking it with garbage bags to sort out things that can go to charity, and things that just need to be trashed.

Sometimes I've seen one of those shows on TV where people bring in professionals to help clean up horrifying houses, and that sparks a primeval urge in me to do it myself, before my neighbors make the call.

Also, I always wanted to have one of those houses that people can just call and say they're in the neighborhood and they're dropping by, and I'm relaxed about it, instead of running around frantically tidying up before they get there.

The problem is that I'm easily distracted, and, instead of finishing one room before then moving on, I re-

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## Picky eaters may need a different kind of helping

Physical, psychological issues can be present, studies show.

By VICTORIA CLAYTON  
CONTRIBUTING WRITER

For ages, parents have negotiated with, bribed and gently threatened their children in an effort to get them to expand their palates. But no matter what tactics are used, the broccoli often remains at the corner of the plate as pizza and chicken nuggets go down with smiles.

Most children will grow out of their picky

phases, but for others, something deeper may be going on. Recent studies have shown that avoiding certain foods may have more to do with psychological, musculoskeletal and sensory issues than behavioral problems.

Jody Stratton, a speech pathologist at the Communication Development Center in Costa Mesa who has worked with picky eaters, said many doctors don't realize that such selectivity may indicate other problems and, most important, that there's help.

"Pediatricians tend to be very lax about a young child's eating," she said. "More often



THINKSTOCK

Most children will grow out of their picky phase, but for others, a physical issue like a weakness of mouth muscles can be the cause, researchers say.

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# RESEARCH: Alzheimer's, Down syndrome link

FROM PAGE 1

UC Irvine has received \$4.7 million from the National Institute on Aging to launch a five-year study this summer aimed at identifying who with Down syndrome is most at risk for developing dementia.

“I think the urgency in part reflects the urgency of Alzheimer’s research,” said Dr. Ira Lott, a pediatric neurologist and lead researcher. “Alzheimer’s is a tremendous national problem. Many people with Down syndrome live productive and happy lives. To have that cut off prematurely by Alzheimer’s disease is a tragedy that we’re trying to prevent.”

The findings could result in better treatment options and yield discoveries that would also benefit the general population.

“Anytime we can shine a light on any aspect of this disease, that is massively important,” said Jim McAlleer, CEO of Alzheimer’s Orange County. “It’s vitally important for those people and their families that we learn how to treat this disease and cure it in that population. Science might learn more about the disease because of the genetic difference in that population. I think it actually can move science forward.”

### EXTRA GENES

People with Down syndrome are born with an extra copy of chromosome 21, which causes intellectual disability and a distinct facial appearance. Chromosome 21 also carries a gene that produces a protein that forms the plaques in the brain that increase the risk of Alzheimer’s.

The triplication of the chromosome appears to prime the brain for Alzheimer’s,



PHOTOS: SAM GANGWER, STAFF PHOTOGRAPHER  
**Newport Beach resident Gerard Fobes will take part this summer in UCI research aimed at identifying Down syndrome patients most at risk for developing dementia.**



**Alzheimer’s has touched the family of Fobes and his parents, Jeanne and Steve.**

heimer’s, with autopsies showing that most people with Down syndrome have the neuropathological indicators of the disease by age 40.

But despite those structural changes, not everyone exhibits symptoms.

“Why do some with Down syndrome become

demented and some don’t?” Lott said of his research focus. “We think this is not only important for Down syndrome but for understanding Alzheimer’s disease.”

Lott hopes to discover what biomarkers predict who will develop dementia so treatment can be intro-

duced early, particularly as new therapies become available. He’s recruiting 100 volunteers over 40 with Down syndrome to undergo cognitive and memory tests, brain scans, blood work and testing of spinal fluid.

“Because of the biology of Down syndrome, there’s a special window here for understanding the process of Alzheimer’s disease,” Lott said.

### VOLUNTEERING

Gerard Fobes, 45, of Newport Beach, plans to volunteer for Lott’s study after losing two childhood friends to Alzheimer’s as well as his maternal grandmother. He doesn’t mind giving blood or remaining still in a confined imaging machine.

“I just like being a part of it,” he said. “I do know my grandma had dementia. A

lot of European elderly have it.”

His mom, Jeanne Fobes, 84, responded, “That’s why you’re doing it, Gerard. You gotta get a cure for us before we get it.”

Gerard Fobes, who works every Saturday at Ralphs, starred in Garth Brooks’ 1993 music video “Standing Outside the Fire.” He loves researching academic topics on his computer and volunteering with his dad at a local food bank.

Jeanne Fobes said she believes her son will be particularly useful to researchers because of his intelligence.

“There’s a whole lot of intriguing stuff going on with Gerard,” she said. “He remembers everything he has researched. He’s just very bright.”

Lott, who has worked with Gerard Fobes in past Down syndrome research projects, said it’s unknown whether high intelligence could lend some protection against Alzheimer’s.

“It’s better, I think overall, to be on the higher functioning side because you probably have a bit more of a brain reserve,” he said.

### DIAGNOSIS

For adults with Down syndrome, the earliest signs of Alzheimer’s may look different because their intellectual disability can at times mask memory loss. They may experience behavior or mood changes as well as difficulty walking.

“Commonly they have a personality change,” Lott said. “People with Down syndrome are typically very outgoing and socially motivated. They lose this interest. They also develop problems with their memory, which are pretty similar

to Alzheimer’s in the general population.”

Some patients express frustration that they can’t think as well as they used to. They also often become very depressed after a friend or roommate dies of Alzheimer’s.

“They understand the loss but they don’t really understand the process,” Lott said.

Lott said Alzheimer’s puts a tremendous burden on parents, who are often older to begin with because the prevalence of Down syndrome is higher for children whose mothers give birth after 35.

For Ruth Russi, the oldest of three, Alzheimer’s eventually stole her cheerful disposition and enjoyment of the simple pleasures in life. Her favorite place was Disneyland, where she would ask to ride It’s a Small World over and over again.

“The things she liked made her really happy and joyous,” John Russi recalled. “You don’t see it in a normal person. Nobody smiles all the time and she did.”

But as her illness progressed, she lost her limited vocabulary, even her favorite word, bird. She could no longer live in her group home and moved to a long-term care facility. She stopped erupting in excitement when she saw her parents and would ignore them when they visited.

After she died, her parents donated her brain to UCI.

“Dr. Lott said her brain will be used for years to come,” June Russi said. “We wanted to help research. She didn’t need it anymore.”

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Is your child ready  
to be left home alone?

It's about more  
than age. Here's  
some advice  
for assessing  
maturity.

By AMY BENTLEY  
CONTRIBUTING WRITER

Most parents with even a shred of common sense know that a 4-year-old is too young to be left home alone for any amount of time, even while a parent runs a short errand. But what about 10 or 12? Are those appropriate ages to leave a child home alone?

California, like most states, does not have a law that says how old a child needs to be to stay home alone. That decision is left up to parents, and it's an issue every family faces at some point.

Leaving a child home alone has some benefits, said Sabrina Schuck, executive director of the Child Development School at UC Irvine.

“Being able to stay home

GETTY IMAGES

The National Safe Kids Campaign recommends that no child under 12 be left home unsupervised.

alone and care for yourself is a healthy part of a child's development and builds confidence in kids,” she said.

The American Academy of Pediatrics lists 11 or 12 as an appropriate age to leave

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JUNGLE BOOK, THE (2016) (PG) (PG) 10:05PM

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ANGRY BIRDS MOVIE, THE (PG) 1225 350 710 850 940

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CAPTAIN AMERICA: CIVIL WAR (PG-13) 1050 1230 120 210 350 440 530 800 850

COMPADRES (R) 10:55AM

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KEANU (R) 1240 310 540 810 1045

MAN WHO KNEW INFINITY, THE (PG-13) 1055 145 435 725 1015

MEDDLER, THE (PG-13) 1050 125 400 655 935

MONEY MONSTER (R) 1130 1245 200 315 430 545 700 815 930 1045

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ALADDIN (1992) (G) 700 PM

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CAPTAIN AMERICA: CIVIL WAR (PG-13) 1120 125 235 440 550 710 755 905 1025

DARKNESS, THE (2016) (PG-13) 1235 305 530 810 1040

HUNTSMAN WINTER'S WAR, THE (PG-13) 920 PM

JUNGLE BOOK, THE (2016) (PG) 1100 1215 300 435 715 955

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SOLEDAO D'BRIEN: THE WAR COMES HOME (PG-13) 700 PM

THE BLACK CAULDRON (1985) (G) 115

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