



# ABC-DS

**Alzheimer's Biomarker Consortium – Down Syndrome**

Springq 2023 | Issue 2

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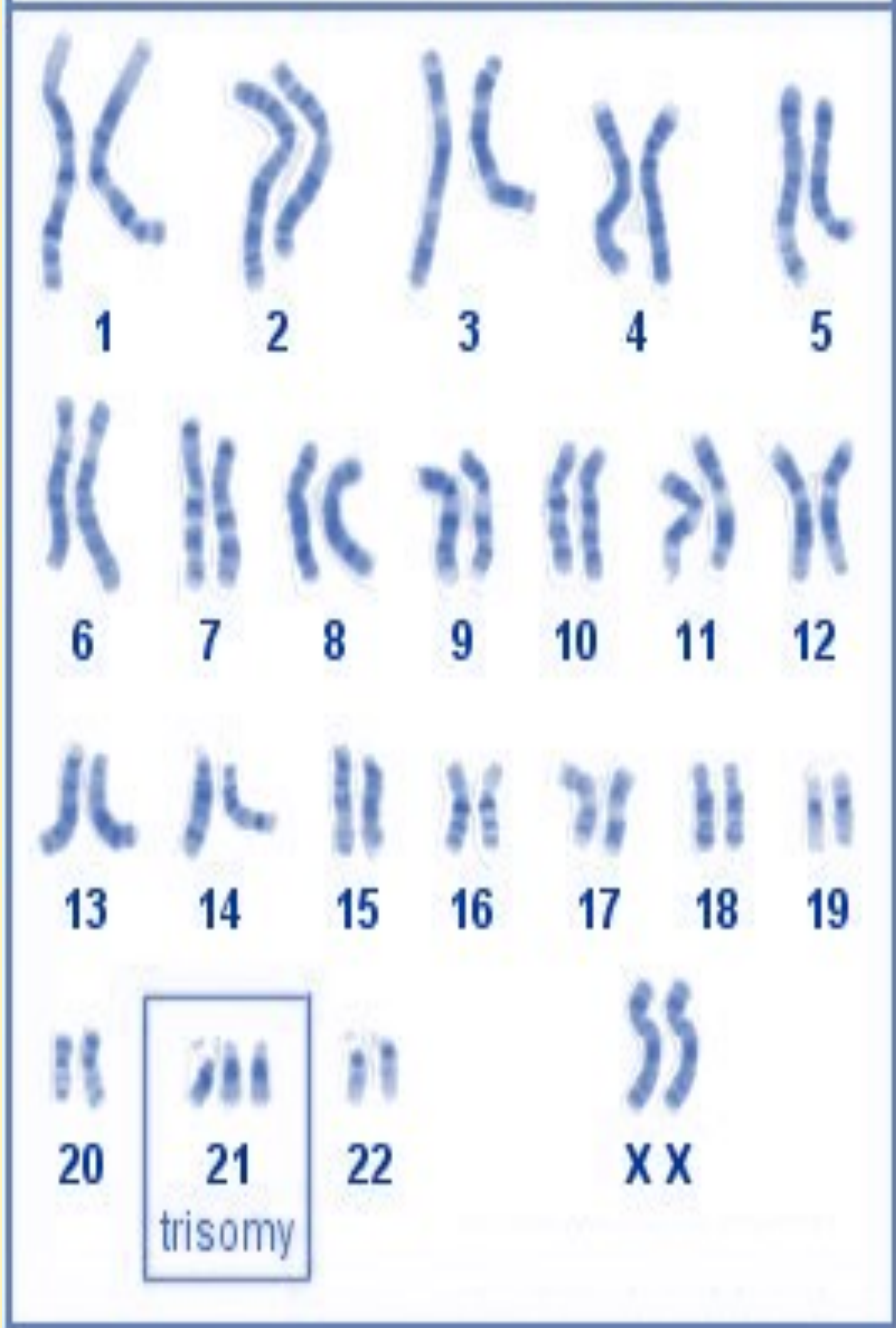
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## Have Fun with ABC-DS

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## Down Syndrome Karyotype



**Picture: Down Syndrome Karyotyping for Trisomy.**  
From [down-syndrome-karyotype\\_orig.jpg \(269×324\) \(mrgscience.com\)](#)



# How ABC-DS came to be...

Some of you have been participating at our sites for many years! ABC-DS is a very large longitudinal study across the US and the UK, examining biomarkers of Down syndrome and Alzheimer's disease in a group of people with Down syndrome, ages 25 and older. You may be wondering how the study you are participating in became the Alzheimer Biomarker Consortium- Down Syndrome (ABC-DS) study. In 2015, the National Institute of Health (NIH) funded two teams of research — Neurodegeneration in Aging Down Syndrome (NiAD) and Alzheimer's Disease in Down Syndrome (ADDs). The collaboration became ABC-DS. The continuation of ABC-DS was funded by the NIH in September 2020, which is the study you are currently participating in!

Despite the changes in name, the growth of our team, and locations, the goal of ABC-DS remains the same, to identify early biomarkers that may herald the onset of Alzheimer's disease. The whole ABC-DS team is hopeful that these biomarkers can be useful to inform clinical trials (like the TRC-DS study) and improve the quality of life in people with Down syndrome and for the general population.

Yours,

Dr. Annie Cohen

(University of Pittsburgh, P. I)

Dr. Elizabeth Head

(University of California, P.I)

*ABC-DS is sup-*

## ***What are Biomarkers?***

A ***biomarker*** is something we can measure in the body. This measurement can tell us more information about the person's body, such as: the presence of a disease or how severe the disease might be.

### ***What biomarkers are being studied in ABC-DS?***

- ⇒ Cognitive (related to the brain).
- ⇒ Genetic (related to genes and chromosomes in the body).
- ⇒ Neuroimaging (related to MRI and PET scans).
- ⇒ Blood-based (related to blood and metabolism).
- ⇒ Fluid (related to Amyloid and Tau proteins).

# The Participant Spotlight.

Here are five participants who happen to be in our study but have way cooler pastimes. Learn more about them as your turn the page.

01 **Ramona and Marcela**

*ABC-DS California - University of California, Irvine*

02 **Christian**

*ABC-DS New York - CUIMC/NYS IRBDD*

03 **Tom and Julia**

*ABC-DS UK - University of Cambridge*

04 **Gerard**

*ABC-DS California - University of California, Irvine*

05 **Lee Ann and Barbara**  
*(In Memoriam)*

*ABC-DS California - University of California, Irvine*



## ***Ramona and Marcela***

### ***The Favorite Sisters***

#### **Why have you decided to participate in the ABC-DS study (in research at UCI)?**

That's a good question...I have no idea...hmm... I'm brave. It makes me feel happy. I participate because I get to see you [researchers]. I like it. People are nice there and you have my money.

#### **Tell me something you are excited about?**

I like going to my new program, Adult Development Center. They took us fishing where I tried my best, but I didn't catch one, somebody else caught it. They also took us to the library where I got some new books to read.

#### **Tell us an interesting story about yourself?**

I'm a nice person.

#### **What makes you happy?**

My exercise, Samba dance class, and reading my books

#### **Tell us some dreams you have for your future?**

I love my boyfriend. I want to keep him forever. I want to get married. He has been asking Marcela about it.

#### **Tell me your favorite things about your sister?**

She's cute and she's the greatest. She's the best sister. She's number 1.

#### **What makes you angry?**

One of my housemates makes me angry. She wants to play staff but she's not. She's bossy.

#### **What makes you sad?**

When I think of my grandparents, my parents and my friends that have passed away.





**What dreams to you have for Ramona's future?**

My dream for my sister's future is that she continues to remain happy and content and socially full life at her group home. I believe this is still possible regardless of the possibility of her developing dementia in the future. I've witnessed first-hand other individuals in her group home transition through the various stages of dementia without any significant impact on their psychological well-being so I know that in the right setting, and with a good advocate it can be done.

**What is your favorite thing about your sister?**

My favorite thing is that she is my sister. That she has a memory of our family history, those that have passed before us. I love that she holds onto the family history. For example, she may be reading the menu at a restaurant, and she will say "Oh, this dish was our dad's favorite". She holds onto the memory of things that are dear for us.

Another thing is that she has a very positive outlook on life. She always says "that's in the past" and I think - *Yeah, that is in the past, where it belongs and it's not important, it doesn't matter.* She has the wisdom to live in the present.

I admire her for the simplicity of how she takes on life's challenges and makes them uncomplicated. I think we all tend to overcomplicate things.

**Why did you decide to donate her brain to our research program?**

We are not doing all this volunteerism to not donate her brain at the end of her life. I understand the value of her brain will have when the researchers can examine the relationships between the clinical and biomarker data collected in ABC-DS and the brain changes seen at autopsy.

**Why have you decided to participate in the ABC-DS study (in research at UCI)?**

UCI was someplace that my mom had found to take Ramona during childhood, and she saved all the original records from those visits. When the opportunity came to participant in a study that affects people with Down syndrome at the other end of life, I thought it just made sense. My mother was a mover, and she moved my sister through childhood and into adulthood, So moms role and my role are like book ends. Now I'm the mover, moving with Ramona into later life, a future that I know includes the significant possibility of her developing Alzheimer's disease.

Also, for many years I was involved in Alzheimer's disease and dementia with my mother and mother-in-law who were both diagnosed with dementia. I think the research going on at UCI (ABC-DS) can possibly result in a cure for Alzheimer's disease. A cure not only for people with Down syndrome, but for all of us. If my sister and I can help further research towards this cure in any way, then we are all in.

## ***Christian***

***Christian give a Movie review about the movie “Love Actually”.***

***We think we should pull out the Popcorn.***

### ***"Love Actually"***

"Love Actually" is a British romantic comedy love story which featured an all star cast. It includes 2002 "About a Boy's Hugh Grant, 2005 "The Lion, Witch and the Wardrobe's Liam Neeson, and 2001 "Harry Potter and the Sorcerers Stone's Alan Rickman.

In the movie, Liam Neeson played a stepfather who goes by the name of Daniel who is grieving the sudden death of his wife. The depressed man is also struggling with raising his stepson. Alan Rickman portrayed as Harry, has a difficult time with spending more time with his own family, as well acting as the boss of a design company. Hugh Grant plays as the workaholic Prime Minister, who doesn't yet quite understand the difference between how important family and Christmas is.

### ***How did I like this movie?***

The film is divided by 9 different love stories. The one scene where Daniel urged Sam his stepson to not be afraid of literally running after the love of our lives is an example for everyone to follow. The camera movement tilted in and out of scenes. The story, as I said before, is divided by 9 love stories, as it followed extremely well with the film.



*“Love Actually” was released in 2003. It is directed by Richard Curtis.*  
*This movie review is one of the many movie reviews Christian does in his spare time.*

FROM THE MAKERS OF  
FOUR WEDDINGS, BRIDGET JONES AND NOTTING HILL  
**THE ULTIMATE ROMANTIC COMEDY**

hugh **grant**  
liam **neeson**  
colin **firth**  
laura **linney**  
emma **thompson**  
alan **rickman**  
keira **knightley**  
rowan **atkinson**



**love**actually

Written and directed by Richard Curtis

PG-13

COMING SOON ACTUALLY

0 1 2 3 4 5 6 7 8 9 10

## *Tom and Julia*

*Tom is the Brave research veteran and Julia is the supportive sibling.*



I have been taking part in the research for the last 4 years. I go to speak with Jess about what I have been doing and I have to do some games and puzzles with her which I really like. When I go for the brain scans, first I have to take off my belt and put it in a locker and then the staff make sure I don't have any metal on me. You can't have any metal near the scanner.

Next I go in a small room and sit in a big chair and I have an injection of special dye. It doesn't hurt! After that I have to wait quite a long time for the dye to go round my body, people talk to me while I am waiting so I don't get bored!

When I go into the scanner room I have to lie down on the bed and all the staff go into the room next door to watch through the glass, I have to lie still for a long time but the staff talk to me to make sure I am ok. It's a bit noisy, the scanner makes beeping and banging sounds but its not too bad, sometimes I fall asleep. My sister, Julia goes too but I am braver than her. I enjoy going. I like telling Jess and the other staff about all the things I do with my family and at work.



When I first heard that the research team was looking for siblings to join the research as ‘controls’ I jumped at the chance. My brother, Tom, had already signed up to take part in the study and I had already heard everything that had been explained to him regarding the research and I felt compelled to sign up! I really enjoy doing the cognitive tests, it’s amazing how such seemingly simple tasks can become so difficult when in a timed environment!

When I have attended the brain scans all of the staff at the Wolfson Brain Imaging Centre are fantastic. They take time to explain the procedure to you and let you know what to expect and there is ample opportunity to ask any questions. The most difficult part is lying still and not speaking for nearly an hour. We are very fortunate in that we live near Cambridge and therefore attending the appointments is easy and my employer is extremely supportive of my commitment to the research and allows me time off to participate when needed.

Taking part in this research with Tom has given us a unique, shared, experience that not many other siblings have. When either of us has been to our appointments we always talk about how it went and what we did. Tom likes to tease me and say he is braver than me when we have been for the brain scans! If anyone is considering getting involved as a sibling control, I would thoroughly recommend it and would be happy to chat through my experiences further.





## Gerard

*Gerard is the Secret Weapon and a Poet ! Whew, what a combo!*

### Why did you decide to participate in ABC-DS?

I love research. I live for research. It's may not be a career, but I love being a volunteer and participating and helping people with Down syndrome and helping scientist learn about Alzheimer's. The research study has a lot to do with the brain. The brain is like a big computer. Brain research is what it's about. Me and you (Eric) are men of science, and we believe that we must serve humanity. I'm helping.



### Interests?

I volunteer at SOS (Share Our Selves) on Mondays with my father to help low-income or homeless people. We pack up food for them, but we also try to nourish their soul. (Gerard's father notes that Gerard has volunteered there since 2006 and each week he ends the team morning huddle meeting with a reminder of why there are volunteering, along with inspirational words to boost their enthusiasm for the day's work.)

For over 30 years I have been the water boy for the Corona del Mar High School football team. Cheering from the sidelines and providing encouragement and support to the players while making sure they stay hydrated. My nickname is "Secret Weapon".







**Have you participated in previous research?**

I've enjoyed a lifetime of research studies since I was 8 years old when I met Dr. Lott at UCI. I think I've been in 4 or 5 different re-search studies.

**Any advice for others?**

Don't dwell on the past or the future. Live in the present. It's reality.

**Anything else you would like to share?**

I enjoy writing poetry. I know I'm not a professional poet, but it just comes from my soul and my heart, and I want to share it. Everything I do is for humanity. I am working on a memoir, my life story. The point is that we all can do something if we set our minds to it. As Yoda said, there is only do...or do not, there is no try. That's the advice I gave my mother many years ago when she told me she was going to try and quit smoking. She listened and was successful quitting.



## ***Lee–Ann and Barbara***

***We would like to Thank the family of Lee - Ann for allowing us to commemorate her.***

**Do you have any life advice that you would like to give others?**

Be grateful, be honest, listen to your heart, enjoy life, be kind to others and don't forget to give thanks when people help you.

**Tell us a fun fact about you.**

Dean Martin sang Happy Birthday to me in Las Vegas when I turned 21.

**How does having Down syndrome make you feel?**

I'm so glad to be Down's. I feel very special. It makes me feel different...I feel special. Sometimes I'm not talking right because it's hard and sometimes I worry too much but people help me with that. Having Down syndrome makes me feel important to the doctors at UCI. I'm so lucky that I'm Downs.

**Why do you participate in research?**

I really enjoy it. It helps me focus my brain. I'm so honored to help other out there that are like I am. Great people at UCI that make me laugh and feel happy and excited. I enjoy my days out there. I would like to do research a lot more. I really enjoy it. The doctors and nurses and all the staff are so nice. And thank you for letting me be a part of your research. Thank you very much. Research is very important for my brain. I really like learning about those machines. Great team in Irvine and I would like to help more if I can. I know my mom and dad would be so proud. I'm so honored to do that. I've had a wonderful life.





Lee Ann and I first met with Dr. Ira Lott at UC Irvine over ten years ago. From this first meeting, Lee Ann was very interested in doing this research. I encouraged her because I thought it would give her a good sense of purpose and provide an opportunity to become involved with a team. We discussed Alzheimer's disease and how it could someday affect her. She loved going to Irvine for the testing and being with Eric. Once when she turned 60, her extended family got to meet Eric and celebrate her birthday which was very special.



Donating Lee Ann's brain was very important to me -- I really think she would be thrilled to know we did. In some ways, the donation provides a continuing legacy of something that she was so proud of and truly believed in. The brain donation is the culmination of her research participation.

I would strongly recommend this program to any individual with Down syndrome. The sense of purpose and camaraderie that came with this research was life changing for Lee Ann and me. The staff at the UCI Down syndrome research program were instrumental in helping my sister to tolerate the COVID pandemic as well as contributing to her happiness and satisfaction in her last few years of life. I miss her every day but feel better about her death knowing her beautiful brain will help someone down the road. Lee Ann gave all our lives purpose, and we were happy to support her. She deserved it. Thank you to all who made my sisters life so, so special.

# ***A Mothers' Worry...***

*by Amy Kolb Tucker*

Trying to be present.

Much is written, lectured, spoken about 'being present'. I've read a handful of books and articles on the topic. I fully comprehend the topic. Am I able to implement this in my 'real life'? Not so much — and these days, that is ever so much more challenging.

I've always been a worrier; usually about future things that might or could happen — things that haven't even happened yet. I try all manner of strategies to be here 'in the now' — to live in Kairos time rather than Chronos time (Thanks, Dawn, for introducing me to the concept). Retirement has certainly helped me live without being beholden to the clock. I revel in sleeping without an alarm, savor my extra cup of coffee in the morning, and indulge in a hike or a spontaneous camping excursion now and then. I'm comfortable with the day-to-day little things.

Alzheimer's.

Katy has Alzheimer's.

Is it Alzheimer's or Alzheimers? Am I even saying it/writing it correctly? People might think I'm ignorant if I don't say it or write it correctly.... My mind could be preoccupied for hours with such a thought.

But, the reality is that Katy has Alzheimer's.

I worry when I see her struggle for words — when will the words stop?

I worry when I see her anxious face. When will the smiles stop?

I worry when she says she doesn't want to go to work. When will she lose interest in going out altogether?

I worry that she won't want to go on the cruise we have had planned for over a year because it's still six months away.

(\*read the rest of the article on <https://medium.com/@amykolbtucker>)





*Katy at a Beach in Southern California. Katy has loved the show “Baywatch” since she was 9 years old.*

In addition to being Katy’s mom, Amy Kolb Tucker is a retired Special Education teacher. Amy has a M.A. in Special Education with a focus on Adapting Curricula and Pedagogy for students with Autism. Now retired, Amy is the volunteer Area Director for the Special Olympics team for Siskiyou County in California.

Amy is also a parent on the ABC-DS Parental Advisory Board. Though Amy is on the board, her daughter, Katy is not enrolled in our study. Katy officially has Alzheimer's Disease.

Amy decided to join the Parental Advisory board to help families as a precaution and help ABC-DS with our resources.

Amy Kolb Tucker can be found on Twitter:

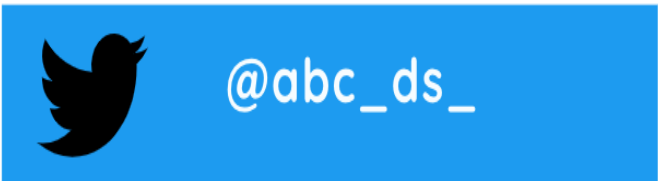
@ AmyKolbTucer2 and on Medium: <https://medium.com/@amykolbtucker>



# Follow Us on Social Media



Let's Get Connected for the Latest Alzheimer Biomarker Consortium- DS News & Updates




# Checkout the Down Syndrome Podcast Series

Welcome to the Down Syndrome Podcast Series provided by UPMC Children’s Hospital of Pittsburgh and hosted by Kishore Vellody, MD, the medical director of Children’s Down Syndrome Center.

The podcasts focus on a wide range of topics related to Down syndrome for parents, caregivers, educators, and medical professionals.

Podcasts are updated regularly and feature discussions with medical experts.

If you have a topic that you would like them to discuss, please send an email to [DownSyndromeCenter@chp.edu](mailto:DownSyndromeCenter@chp.edu).



### Down Syndrome Center Podcast

Kishore Vellody, MD

Health & Fitness

★★★★★ 4.9 • 49 Ratings

Listen on Apple Podcasts ↗

100 episodes

This podcast contains information for caregivers and providers regarding Down syndrome. Hosted by Dr. Kishore Vellody, Medical Director of the Down Syndrome Center of Western Pennsylvania and former President of the National Down Syndrome Congress.

JUN 2, 2022

#### #133 - Catching Up with The Improvaneers (with Rob Snow)

Rob Snow (creator and founder of The Improvaneers) returns on the podcast to give us an update with how its going on the comedy show, the impacts of COVID, and the vision for the program. You can get more information on The Improvaneer Method by listening to our prior podcast #61 found at...

▶ **PLAY** 22 min

MAY 19, 2022

#### #132 - Down Syndrome Diagnosis Network (with Jen Jacob)

Jen Jacob, Founder and Executive Director of the Down Syndrome Diagnosis Network (DSDN) joined the podcast to talk about their work in the area of information and resource sharing for families. You can get connected to DSDN by going to <https://www.dsdiagnosisnetwork.org>. If you have any topics...

▶ **PLAY** 20 min

# ABC-DS

U	N	U	G	N	I	Z	A	M	A
Y	T	I	V	I	T	A	E	R	C
C	H	R	O	M	O	S	O	M	E
Q	G	O	A	N	Z	P	B	C	Y
E	V	U	M	I	E	E	R	A	M
F	U	P	Y	H	D	R	I	P	O
I	Y	V	L	A	R	F	E	A	S
L	Y	F	O	P	Q	E	H	B	I
B	N	F	I	P	F	C	S	L	R
T	V	U	D	Y	Z	T	Q	E	T

Amazing    Amyloid    Capable    Chromosome    Creativity    Happy    Life  
Perfect    Trisomy



## ABC-DS Sites

University of Pittsburgh (Coordinating Center), Pittsburgh, PA

Columbia University Irving Medical Center, New York, NY

The New York State Institute for Basic Research in

Developmental

Disabilities, Staten Island, NY

Harvard Medical School, Massachusetts General Hospital,

Boston, MA

University of Wisconsin-Madison, Waisman

Center, Madison, WI

University of Cambridge, Cambridge, UK

University of California, Irvine, Irvine, CA

University of Kentucky: Sanders-Brown Center on Aging and the

Kentucky Neuroscience Institute, Lexington, KY

Washington University in St. Louis School of

Medicine, St. Louis, MO

Visit Us At:

[www.nia.nih.gov/research/abc-ds](http://www.nia.nih.gov/research/abc-ds)



The Alzheimer Biomarkers  
Consortium-Down Syndrome  
(ABC-DS)