



DETERMINED

FIGHTING ALZHEIMER'S

Director – Melissa Godoy
Producers – Therese Barry-Tanner & Eileen Littig

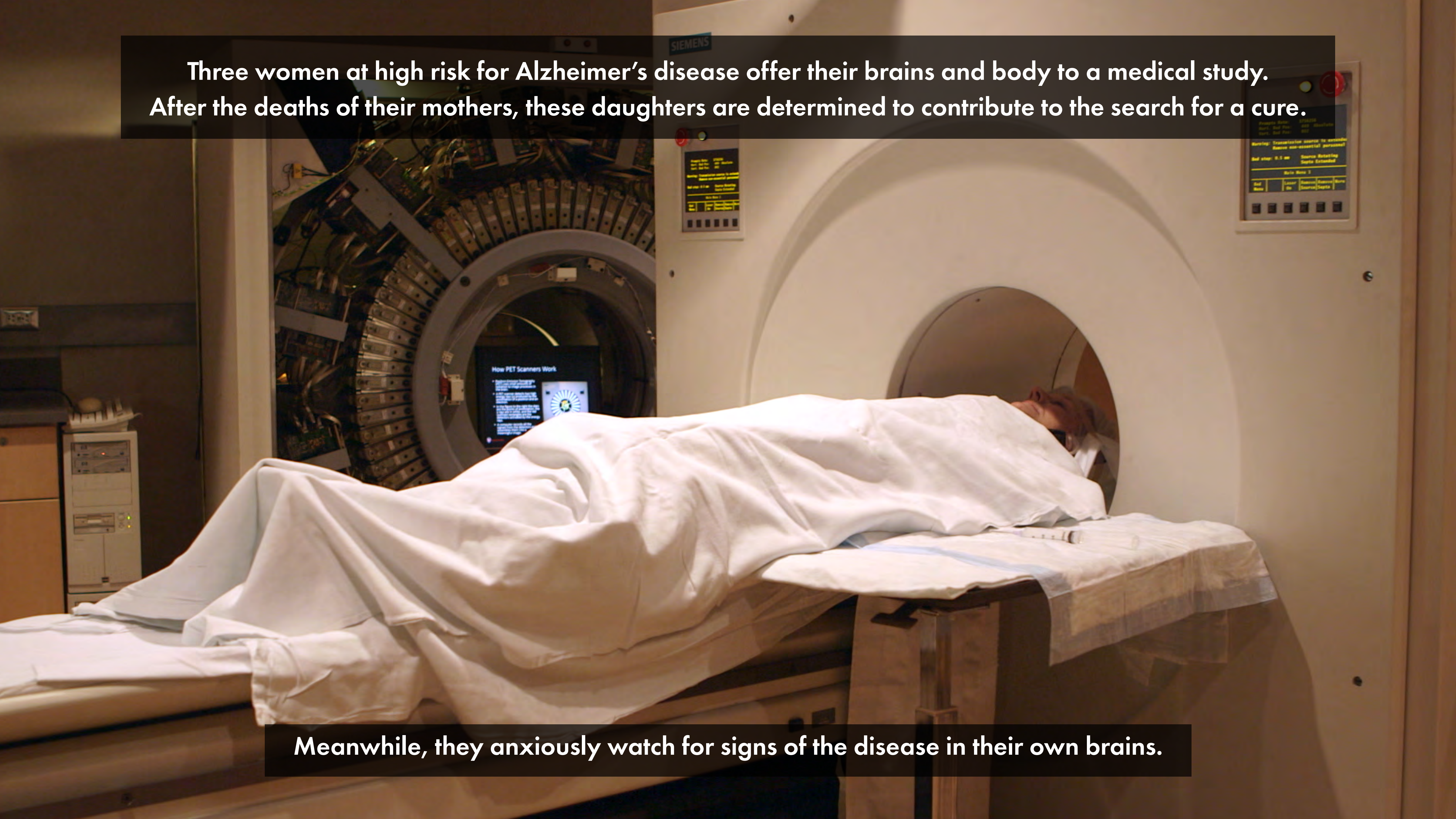


**"...what lifts DETERMINED above the level of most science documentaries is the storytelling.
THE INTIMACY IS POWERFUL, as if the families have invited us into their homes."**

- Catherine Caparello, *Isthmus*



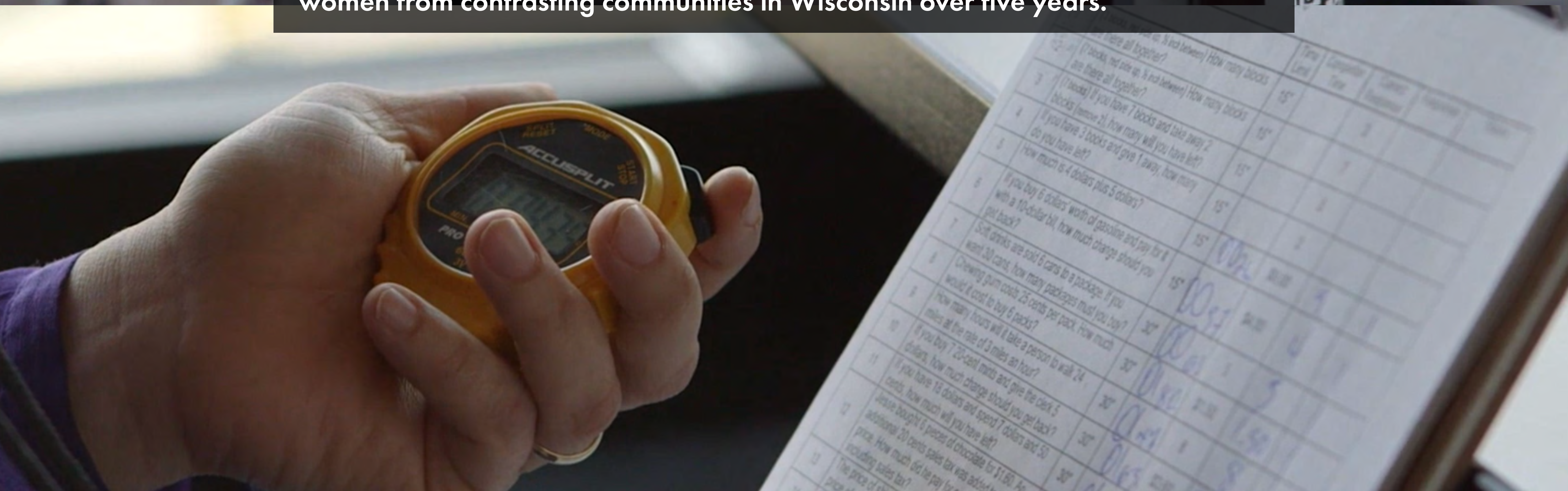
Three women at high risk for Alzheimer's disease offer their brains and body to a medical study. After the deaths of their mothers, these daughters are determined to contribute to the search for a cure.



Meanwhile, they anxiously watch for signs of the disease in their own brains.

SYNOPSIS

Filmed in an observational style with supplementary interviews, the film follows women from contrasting communities in Wisconsin over five years.





Barb and her large family take turns caring for their dying mother in a rural corner of the state.



KAREN struggles to raise her adolescent son after her own mother's passing.



SIGRID, a retiree in a college town, focuses full-time on adopting a lifestyle that she believes can stave off the disease.



With nuance and tenderness, the film interweaves the scientists' quest to find a cure with the personal ups and downs of these women's lives.

The intimate access to all of their stories reminds viewers that Alzheimer's is a disease battled on many fronts: in a laboratory, in a home, in a marriage, in a mind, and in one's hopes and fears about the future.

THEMES AND CHARACTERS

Our characters' stories represent enduring and emerging truths about the Alzheimer's crisis.





BARB

Barb drives five hours each way to help care for her mother, Irene, who is in the last stages of Alzheimer's. The family has brought Irene back from a nursing home to their house in rural Wisconsin. Barb's father, at 80, is the lead caregiver in this family that includes three grown daughters.

The family navigates the perils of strained relationships and Irene's frailty as she slides into her final days. Despite some head-butting with their dad, the sisters carry on with good humor. But deep down, Barb is terrified that she will be next to inherit the disease. She joins the study.



KAREN

In Milwaukee, Karen grieves the death of her mother, whom she cared for during her 12-year battle with Alzheimer's. During that time, her son Xavier's needs were often left behind. Now, Karen wants to make up for lost time.

She enrolls in the study. But aftershocks from these hard years erupt. Xavier is expelled from high school. Her marriage is strained.

Xavier begins the next year at an alternative school. Karen channels her experiences into helping others with Alzheimer's disease. With steady effort, Karen and Xavier seek victory in remarkable ways.

Families Emerge as Silent Victims Of Tuskegee Syphilis Experiment

By CAROL KAESUK YOON

TUSKEGEE, Ala., May 9 — It has been 25 years since the nation learned that more than 400 black men infected with syphilis went untreated for decades in a federally financed experiment in this rural Southern town laced with sandy

tric utility, recounted his father's ordeal as he sat in the kitchen of his home just across the border in Columbus, Ga. "It was one of the worst atrocities ever reaped on people by the Government," he said. "You don't treat dogs that way."

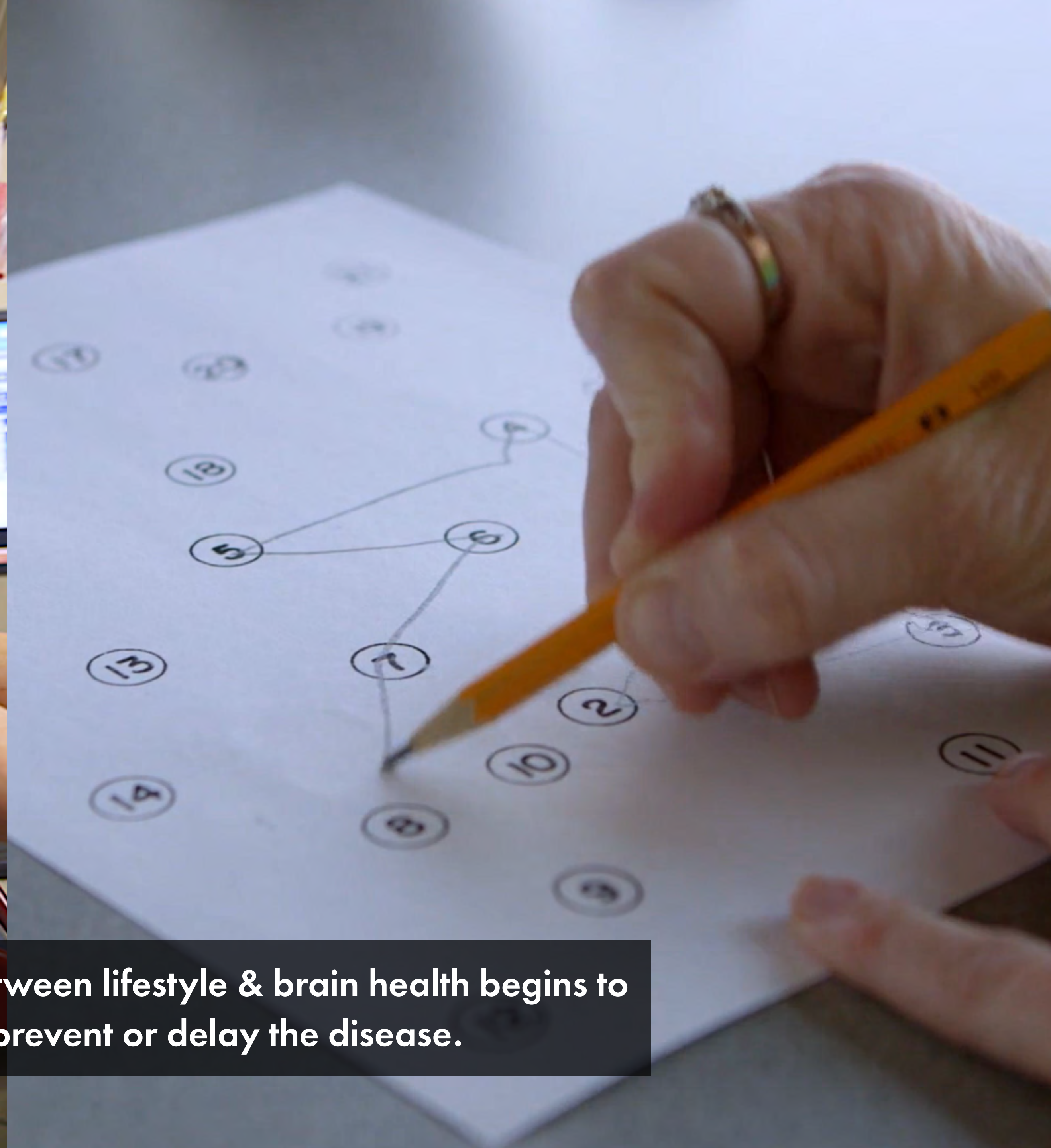
The legacy of unethical medical research inhibits the search for a cure.
African-Americans are up to twice as likely to get the disease as Caucasians.
The study badly needs more African-American subjects.



GINA GREEN-HARRIS

Gina Green-Harris heads the Milwaukee office of the Wisconsin Alzheimer's Institute. She reminds the scientists about the sinister history of research on Black Americans. There are so few Black volunteers, Gina says, because recruiters don't "know how to ask (knowledgeably and respectfully)."

Gina forms a Community Advisory Board. Besides being a watchdog, these Milwaukeeans bring new humanistic perspectives to the disease that extend beyond research. For example, they form a choir made up of people with Alzheimer's and their caregivers. When the choir sings in public, not only is it a joy for them, but it shows how to live openly with dementia – without stigma.



New evidence of a relationship between lifestyle & brain health begins to reveal possible ways to prevent or delay the disease.



SIGRID



Sigrid, 72, is afraid that she's experiencing the early stages of the disease. Her mother died of Alzheimer's, so Sigrid is in the test group. Her husband David, whose parents did not have Alzheimer's is in the control group.

Sigrid decides to fight back with healthy eating and exercise. She also begins a quest to clean out the couple's lifetime of personal belongings. David is not enthusiastic about the family's new self-improvement plan.

Despite resistance from her husband, Sigrid soldiers on.



DR. OZIOMA OKONKWO

Sigrd participates in the Fitness, Aging, and the Brain study led by Dr. Ozioma Okonkwo, one of the researchers at the Wisconsin Alzheimer's Institute

Now we get an inside look at the scientific method, from the moment when Dr. Okonkwo proposes his hypothesis. Is there a relationship between physical activity and Alzheimer's biomarkers?

He conducts a series of experiments. Results unfold on camera.

Using the human subjects, the scientists learn some of the most important recent findings in the field today.





This is the latest in the fight against Alzheimer's – by those with a very personal stake in the battle. How soon will an answer be found? For Barb, Karen, and Sigrid, beating the disease is a race they need to win.

Brains and hearts

"Determined" is a smart, compassionate look at the stories behind UW’s long-term Alzheimer’s study

BY CATHERINE CAPELLARO
DECEMBER 8, 2020



In the documentary "Determined," Doren, left, chooses to bring his wife, Irene, home to care for her at the end of her life.

As the daughter of someone who died from dementia-related causes, a film about Alzheimer’s disease is not going to be an easy watch. But I know I am not alone. According to [UsAgainstAlzheimer’s](#), 5.7 million Americans are living with the disease right now. Those of us who cared for relatives with dementia know how truly awful the disease can be, and our greatest fear is that it will happen to us.

No matter what your experience with dementia, I believe you should make a point of watching *Determined*, the smart and compassionate film that documents the groundbreaking research happening at UW-Madison. The film features subjects enrolled in the 20-year clinical trial of adult children of parents who died from Alzheimer’s, called Wisconsin Registry for Alzheimer’s Prevention (WRAP). At the heart of the movie are stories of compassion and resilience. The all-female filmmaking team gained intimate access to families struggling to care for partners and parents with dementia. They are participating in rigorous studies to try to document changes in their cognitive abilities to help researchers gain knowledge about how to prevent the disease.

How 3 'Determined' Green Bay women are giving a voice to anguish, resilience of Alzheimer's families with film 10 years in making

[Kendra Meinert](#), Green Bay Press-Gazette Published 2:31 p.m. CT Feb. 25, 2021



"Determined" director Melissa Godoy, a Green Bay East High School graduate, left, and producer Therese Barry-Tanner of Green Bay are among the eight women filmmakers behind the documentary. (Photo: Courtesy of Melissa Godoy)

GREEN BAY - It started as a lunch meeting between two strangers 10 years ago at Not By Bread Alone, but for Therese Barry-Tanner, the inspiration for making a documentary about families affected by Alzheimer’s disease began long before then.

Her mother was diagnosed in 2001, shortly after her parents’ 50th wedding anniversary. She spent years helping her dad care for her, until he was no longer able to. On the day Barry-Tanner and her sister arrived to help move their mother to a nursing home, he told them he wouldn’t be going along.

“He couldn’t do it. He couldn’t take her there. My sister and I had to do it,” Barry-Tanner said. “Hardest day of my life.”

The emotional pain her dad suffered as a caregiver also took a physical toll. He had become so focused for so long on the care his wife needed he had neglected his own health. Less than a year after Barry-Tanner’s mother moved into a nursing home, her dad was diagnosed with terminal cancer. He died six months later.



NOTES FROM THE PRODUCER

I lost my mother to Alzheimer's disease in 2008. I spent seven years (five with my dad) helping to care for her. My father died of undetected cancer in 2006. He was so focused on her, he wasn't taking care of himself.

Two years after her diagnosis, I learned of a study at the University of Wisconsin that was accepting new recruits of children of a parent with Alzheimer's. I signed up. The first research visit focused on almost four hours of memory testing, and everything was new and exciting. But starting with visit two, you get anxiety. The reason is simple – the stakes are high for a child of a parent with the disease (we're 2.5 times more likely to get it ourselves). But I've stuck with it.

Because of my personal experience and the difficulties my family faced in caring for my mother, I want to tell the story of how this disease affects families. I want to convey accurately where we really are on the path to a cure. Over the 19 years since my mother was diagnosed, I've read many headlines that purported a new drug was around the corner. But it's 2021, and there still is not a cure. All the clinical drug trials performed in the past 10 years have failed. That's the headline.

Alzheimer's is the only one of the top 10 leading causes of death without a cure. Because of our world's rapidly aging population, it's estimated that by 2050 the number of people with the disease will triple: to 131.5 million worldwide.

If it hasn't already, Alzheimer's disease and related dementia will somehow impact every family and community. One of the most urgent needs absolutely critical to finding a cure soon is for more people to join in research and clinical trials.

However, stigma is slowing down progress. Fear of discrimination discourages many with early stage Alzheimer's from participating in research. And the history of unethical medical experiments on people of color has created mistrust. New approaches to engaging people in life-saving research is desperately needed. Without full, diverse and democratic participation, the search for a cure will fail.

Documentaries that have focused on Alzheimer's research have mostly done it through talking heads and fear. And while people with the disease and their families have sometimes been included, this angle on research has rarely been seen as vérité. I want to show it like it is – the full 360-degree view including the research component. I want to engage audiences so that they think and feel differently about Alzheimer's, including with hope. From this experience, I believe viewers will be compelled to take their own personal action to be part of a movement that is working to change the trajectory of the disease.

– Therese Barry-Tanner, Producer





ARTISTIC APPROACH

This film is about ordinary Midwesterners doing important, anonymous work. Our camera is grounded, close to the earth, eye level. Single camera, small crew, quiet. The story begins observationally, embedded with a family taking care of their mother. We follow three different families living with Alzheimer's disease and its aftermath. We're in their kitchens, cars, and exam rooms. The crossroad for these families is the research wing at the University Hospital.

The hospital is also where meet the scientists. They work as a team, led by the uncertainties of their study. And while we cannot follow every aspect of this massive research, we follow what is most visible and active: the Exercise Study led by Dr. Ozioma Okankwo.

In a close-up way, DETERMINED weaves the study's quest to find a cure into the personal quests of the participants. It's about the guts of science and life as told by the people in the film. They are family. Relationship clashes show their determination. They face setbacks, but they rally forward. A favorite aspect is the natural humor that arises from observational scenes of relationships, especially in Sigrid and David's story. David's resistance to everything Sigrid tries is funny and relatable. By us not interfering and by observing with quiet access, we captured many scenes that are valuable and touching beyond Alzheimer's disease. The participants are easy to relate to – they have wonderful human quirks, and the story is rich. They change over those five years.

DETERMINED shows what makes a family fragile or resilient to a brutal, shared dilemma.

– Melissa Godoy, Director



PROJECT STAGE AND TIMELINE

Principal photography began in 2013, and seven years later, we're into our limited festival run. The festival cut is 74 minutes with 5.1 surround sound. A broadcast cutdown is forthcoming.

During our story development, we worked with two consulting producers – Maggie Bowman and Julia Reichert; and three consulting editors – Jim Klein, Jaime Meyers Schlenck, and Gordon Quinn. We also had a transformative session with a rough cut at Kartemquin Labs.

Our world premiere was through the 2020 Wisconsin Film Festival. We also are screening in 2021 at the Female Eye Film Festival in Canada, the Raw Science Film Festival in Costa Rica, DOCUTAH, and the Green Bay Film Festival.

MARKETING STRATEGY

Our marketing strategy is tied to impact.

We already have a soft social impact campaign underway with our website and social media, and we will continue to build it.

Stimulating change – in all regions: urban, rural, and to all ethnic diversity is vital to our vision.

We want to use the film to change the trajectory of Alzheimer's disease in the world. Our marketing includes the limited festival run where we hope to build audiences and influencers. We hope that even a modest festival/impact run will boost awareness of DETERMINED.



INTENDED AUDIENCE

The target audience is baby boomers and their families. Boomers are now heavily caregiving for parents and coincidentally, most at-risk for future Alzheimer's. One in ten Americans age 65+ has the disease. As boomers continue to age, they too, are predicted to acquire it on pace.

Or, on the other hand. . . with insight and coordinated effort, baby boomers could instead be the first generation to beat it!

We're addressing the needs of this audience by showing them peers who are going through the same things they are, but we're also empowering them by showing, through story, how they can change that future.

Several of us on the film team are baby boomers, and our impact access includes all the organizations we've connected with. We've been developing communication strategies through social media. Broadcast television continues to be popular for baby boomers, as is online news and social media.

We plan to use it all.



AUDIENCE ENGAGEMENT & SOCIAL IMPACT

After people see our film, we want them to (any of):

- Improve lifestyle choices to enhance their own brain health.
- Support families who are living with Alzheimer's disease and its aftermath.
- Participate in dementia-friendly communities, with varied cultural diversity.
- Enroll in a clinical trial.

The US National Plans to Address Alzheimer's Disease has, as its first goal, to prevent and treat Alzheimer's disease by 2025, a vision to which all G8 countries have committed. All our desired action outcomes lead toward that goal. Our film can incite courage to do things differently.



During the making of this film, we sought relevance and accuracy. We solicited feedback by screening emerging cuts with individuals from:

Leaders Engaged on Alzheimer's Disease – LEAD Coalition an activist group of more than 90 Alzheimer's organizations in the United States. Executive Director Ian Kremer has been especially helpful.

International Neuropsychological Society a professional organization that promotes the international and interdisciplinary study of brain-behavioral relationships throughout the lifespan.

Alzheimer's Association the leading voluntary organization in Alzheimer's care, support, and global research.

We shared a late rough cut with **Keith Fargo, Ph.D.** former Director of Scientific Programs & Outreach, as well as with several insightful members of the communications team.

Additionally, we shared cuts at various stages and solicited feedback from members of the **Alzheimer's Association Wisconsin Chapter, Miami Valley Chapter**, and the **Greater Cincinnati Chapter**.

Susan Peschin, MHS, President & CEO, Alliance for Aging Research a national U.S. organization dedicated to accelerating the pace of scientific discoveries and their application to improve aging and health.

Sara Barsel, Chairperson, Roseville MN Alzheimer's & Dementia Community Action Team a ground-breaking municipal group that supports family, caregivers, and people with dementia.

Lori LaBey, Founder, Alzheimer's Speaks radio host and consultant recognized as the #1 online influencer in the U.S. for Alzheimer's by Sharecare and Dr. Oz.

WRAP's Community Advisory Board, Milwaukee



KEY CREATIVE PERSONNEL

Director/Cinematographer/Editor: Melissa Godoy

Godoy was Line Producer for the Oscar-winning documentary feature, *American Factory* (Netflix) by Steven Bognar & Julia Reichert and its prequel, *The Last Truck* (HBO). She was also Line Producer for Bognar and Reichert's *9to5: The Story of a Movement* (Independent Lens) and the Emmy Award-winning series, *A Lion in the House* (Independent Lens/Netflix). She was a cinematographer for *Election Day* by Katy Chevigny (POV); for the short docs *Making Morning Star* and *Sparkle*; and for Andrea Torrice's *Trees in Trouble* (PBS World Channel). Godoy's directing includes a feature documentary about creative aging, *Do Not Go Gently*, which aired on PBS stations for 12 years through American Public Television. Godoy is a Residency Artist with the Ohio Arts Council's Arts Learning Program. With their support, she directed two fiction films with residents and staff at an Alzheimer's daycare prior to embarking on this film.

Producer: Therese Barry-Tanner

Therese is a first-time filmmaker and an Alzheimer's disease human research subject, like the people in our film. She understands the disease at an intimate level; in 2001, she began assisting her father in caring for her mother, who was just diagnosed with Alzheimer's. *DETERMINED: Fighting Alzheimer's* began as Therese's idea in 2011, after her mother died. She spearheaded the search for funding and the legal clearances to film intellectual property in a hospital setting. She's a creative producer, integral to the storytelling and editing. She also served as sound/grip/interviewer on many shoots. Prior to producing, Therese worked in healthcare, with over 30 years in program and project management at a U.S. Fortune 500 Company, Humana, Inc. Her most recent projects specialized in healthcare reform and physician quality assurance.

Co-Producer: Eileen Littig

Eileen Littig is an independent producer and former Director of Northeastern Wisconsin In-School Telecommunications. With Wisconsin Public Television, she produced social issues programming and has been recognized with two Midwest Emmys. Over her career, she produced numerous creative and important programs for youth, including *Teen Connection*, which aired live for 30 years. Littig earned two Gold Medals from the Corporation for Public Broadcasting, one for *As We Learn to Fall* (1989), about death education, and the other for *Sexual Orientation: Reading Between the Labels* (1992). She was also Co-Producer for *Do Not Go Gently* (2007) narrated by Walter Cronkite, which received a National Media Award from the American Society on Aging. Littig serves on the Wisconsin Educational Communications Board, the Brown County Aging & Disability Resource Center Board, and is a community activist.



Composer/Sound Designer: Brendon Anderegg

Anderegg is a composer and sound designer who has worked on film and television projects with producers and directors including Laura Poitras, Jose Vargas, Seth Skundrick, Stephen Maing, Susan Werbe, and Miao Wang. Highlights include: *102 Minutes That Changed America* - Siskel Jacobs Productions documentary about the events of 9/11, winner of four Primetime Emmy awards and the most watched special ever on the History Channel; *The Price of Gold* - Nanette Burstein's ESPN 30 for 30 documentary about Tonya Harding and Nancy Kerrigan; and *Crime + Punishment* by Stephen Maing.

Sound/Grip: Shawndra Jones

Shawndra's previous experience included working on *Contemporary Color* by the Ross Brothers (Amazon Prime), producer/shooter/editor and sound artist for *Reinvention Stories* (NPR), and Cincinnati sound engineer for *The New Black* (Independent Lens) by Yoruba Richen. She has contributed to the Kirby Dick 2018 documentary *Bleeding Edge* and the 2020 Oscar-winning feature, *American Factory* (both on Netflix). Jones is a graduate of Wright State University's Motion Picture Program and is a news broadcast director at WBDT and WDTN-TV in Dayton, Ohio.

Sound/Grip: Amy Kruep

Amy Kruep, RNC, DCP has worked with the older adults for more than 30 years, particularly those with Alzheimer's disease and dementia. She was a nurse manager at a nursing home in Cincinnati, when she created the Success Through Arts & Environment dementia program. Kruep served on the Alzheimer's Association Greater Cincinnati Public Policy Committee and is a regional trainer for the national TimeSlips™ creative storytelling program. Partnering with Godoy, Kruep produced two short fiction films with participants at her Alzheimer's daycare. Created by writers and actors with dementia, *Until Sadie Blotz* (2012) screened at the Positive Aging Conference in Los Angeles and the American Society on Aging Conference in Chicago. Amy cared for her father through his last days with Alzheimer's disease.

Impact Producer: Karen Durgans, LPC

Karen was Associate Producer and National Outreach Coordinator for *A Lion in the House*, about childhood cancer (ITVS/Independent Lens). The Impact Campaign lasted almost 10 years and included a congressional screening, the creation of educational modules used by 6,500+ health care professionals, along with national conversations and new initiatives in childhood cancer care. After that, Durgans was a field researcher for the U.S. Financial Diaries Project. Currently, she is a therapist for Compass Point Counseling Services. Durgans cared for both her stepfather and mother during her family's journey with dementia.

Creative Consultants:

Maggie Bowman Consulting Producer

Julia Reichert Consulting Filmmaker

Gordon Quinn Consulting Editor

Jaime Meyers Schlenck Consulting Editor

Jim Klein Consulting Editor



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