How much do you sacrifice to survive?

IN THE FAMILY

A film by Joanna Rudnick

IN THE FAMILY

SYNOPSIS

At 27, filmmaker Joanna Rudnick tested positive for the BRCA mutation. She now faces an impossible decision: remove her healthy breasts and ovaries or risk incredible odds of developing cancer.

Armed with a positive test result that leaves her essentially "a ticking time bomb," she balances dreams of having her own children with the unnerving reality that she is risking her life by holding on to her fertility. IN THE FAMILY follows Joanna as she takes us on a journey through the unpredictable world of predictive genetic testing.

Turning the camera on herself, Joanna bares her conflicting emotions about preventative surgery and the potential consequences. Turning the camera on her new relationship, she and her partner capture a young couple falling in love in the shadow of the mutation. Turning the camera on the company that owns the patents to the BRCA genes, she questions their control over access to the test. Along the way, she looks to other women and families dealing with the same unbelievable information.

Intensely personal and timely, IN THE FAMILY is a groundbreaking investigation that attempts to answer the question: How much do you sacrifice to survive?

Producer / Director: Joanna Rudnick
Date of Completion: February 2008
Running Time: 83 Minutes
US Distribution (Television):
Independent Television Service (ITVS)
US Broadcast: P.O.V. October 2008

ITVS KARTEMQUIN FILMS KTQ POV

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IN THE FAMILY

CREDITS

WRITTEN, PRODUCED, AND DIRECTED BY:
Joanna Rudnick

PRODUCER, EXECUTIVE PRODUCER
Gordon Quinn

CO-PRODUCER
Beth Iams

EDITOR
Leslie Simmer

ORIGINAL MUSIC
Erin O'hara

ORIGINAL ANIMATION
Samantha Olschan

OPENING TITLES
Dizzy Giant

CINEMATOGRAPHY
Dana Kupper
Gordon Quinn
Ines Sommer
Cynthia Wade

ADDITIONAL CAMERA
Neil Barrett
Beth Iams
Joanna Rudnick

SOUND
Zak Piper

ADDITIONAL SOUND
Judy Karp
Paul Rusnak
Mary Wong

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IN THE FAMILY

CREW

Joanna Rudnick
(Director/Producer/Writer)

IN THE FAMILY is Joanna Rudnick's directorial debut. The film traces her personal journey of testing positive for a deadly genetic mutation. Joanna has a background in science journalism and film production. In addition to her role as Director of Development at Kartemquin Films, she is producing *Prisoner of Her Past* –a film that follows Chicago Tribune journalist Howard Reich's attempt to uncover his mother's tragic Holocaust childhood in order to understand why she is reliving it 60 years later.

Before returning to Chicago, Joanna co-produced a film on war photographer Robert Capa for the American Masters series. *Robert Capa: In Love and War* (2003) was broadcast on PBS and the BBC, premiered at the 2003 Sundance Film Festival, was the presenting film for the 2003 Emmy award for Outstanding Nonfiction Series, and received the Voice of Humanity award at the Mountainfilm Festival.

Prior to her role on the Capa project, Joanna worked for American Masters for three years contributing to numerous films including *Juilliard*, *Ella Fitzgerald: Something to Live For* and *Joe Papp: In Six Acts*. Joanna also worked to help research and develop a 6-part series on the American novel, funded in part by the National Endowment for the Humanities.

Joanna received a Master's degree in Science and Environmental Journalism from New York University and a Bachelor's degree in English from Northwestern University. She has written for several publications including *Audubon Magazine, The Artful Mind, The Berkshire Record* and *Humanities*. Prior to her work in production, Joanna served as an AmeriCorps volunteer, implementing project-based environmental curriculum in the San Francisco Public School System. Joanna currently sits on the Illinois Humanities Council's Steering Committee on Genetics, helping to create programming for "Future Perfect: Conversations on the Meaning of the Genetics Revolution" –a state-wide series exploring the new science of genetics.

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Gordon Quinn (Producer/Executive Producer)
President and founding member of Kartemquin Films, Gordon Quinn has been making documentaries for over 40 years. Roger Ebert called Kartemquin's first film *Home For Life* (1966) "an extraordinarily moving documentary." At Kartemquin, Gordon created a legacy that is an inspiration for young filmmakers and a home where they can make films that investigate and critique society. Kartemquin's best-known film, *Hoop Dreams* (1994) was executive produced by Gordon.

Recent works include *Stevie* (2003), for which Gordon, who was the film's executive producer, producer and cinematographer, won the Cinematography Award at the Sundance Film Festival, *Five Girls* (2001), *Refrigerator Mothers* (2002), and *Vietnam Long Time Coming* (1999), the story of disabled and able-bodied Vietnamese and American veterans on a journey of reconciliation. Broadcast on NBC, the film won a National Emmy and the Director's Guild of America's award for Best Documentary. Gordon executive produced *The New Americans* (2004) and directed the Palestinian segment of this award winning seven-hour PBS series, and recently produced *Golub, Late Works are the Catastrophes* (2005).

Leslie Simmer (Editor)
Leslie has been Director of Post Production and an Editor at Kartemquin Films for over seven engaging years. Most recently, she was co-editor with Steve James on the feature documentary *The War Tapes* (2006) that won Best International Documentary at both the 2006 Tribeca and BritDoc Film Festivals. Just prior to that she wore dual hats on the seven-part PBS series *The New Americans* (2004) as both Series Story Editor and Post Production Supervisor. Leslie received her BA in Communication/Theater Arts (Phi Beta Kappa) from Kalamazoo College in Michigan, and completed graduate work in film at Columbia College, Chicago.

Beth Iams (Co-Producer)
Beth is the Director of Project Research at Kartemquin and has been working with company since 2005. In addition to her role as co-producer of *In the Family*, Beth is also coordinating the outreach and education campaign around the film. Previously, Beth worked as the Senior Researcher and Associate Producer for Peabody Award-winning York Zimmerman Inc. on international political documentaries. *Orange Revolution*, called "the most convincing film to date" about the 2004 civic uprising in Ukraine, has appeared in numerous film festivals. *Confronting the Truth*, a film exploring truth commissions and the challenges of transitional justice in Peru, East Timor, South Africa, and Morocco, recently screened at the United Nations and has been translated into Arabic, Bosnian, and Kurdish. Beth graduated with honors from Duke University with degrees in Public Policy and Psychology, and has lived and worked in South Africa, Thailand, and Barbados.

IN THE FAMILY

DIRECTOR'S STATEMENT

When I found out that I carried the BRCA genetic mutation that drastically increases my odds of getting breast and ovarian cancer, the last thing I wanted to do was talk about it. The thought of telling my closest friends made my stomach turn. So I hid the piece of paper that said "positive for a deleterious mutation," and did everything possible to forget that I was basically a ticking time bomb.

"They give you the information and then they're like, 'Don't Panic. Don't be neurotic. Don't be paranoid.' But your body can go off at anytime, and that pressure starts right away." It's hard to believe that a few years later I would be saying these words on camera.

When I set out to make **IN THE FAMILY** in late January of 2003, after traveling to the Sundance Film Festival with a documentary that I had co-produced on the war photographer Robert Capa, I had no intention of "starring" in my own movie. I spent months trying to find a young, unmarried woman with the mutation who had not had surgery and was willing to "come out" on camera. I came up empty. This is when I realized that I needed to use my own story to make the film. I was still reluctant, though. I wanted to find someone to fall in love with and was afraid that once I had gone public with my mutation, it would be more difficult to start a new relationship. I was right. I met a guy online that I really liked; before our first kiss, he Googled me and found the mutation. I did the only thing that made sense —I turned the camera on the relationship.

While trying to figure out how to have a relationship and live with this crazy information, I looked to other women for answers: Linda, as she was dying of cancer, teaches me not to mess with life; Martha works tirelessly to keep African-American women in the fight against breast cancer despite trying to battle the disease without health insurance; Olga, a young mother, is so paralyzed by the fear of getting cancer that she can hardly bring herself to test; and the Hanke sisters, three young women who refuse to let different test results tear them apart.

The women were the most important part of the story, but not the entire story. Politics and the business of genetic testing also played a role. I confronted the biotech company that owns the patent on the BRCA genes, and testified in Washington D.C. for legal protection against genetic discrimination.

In the end, it was much easier to disclose that I had a mutation than to remove healthy body parts and sacrifice my dreams of having a family. **IN THE FAMILY** captures a time when science can tell us how we will likely die, but not what to do about it.

Joanna Rudnick September 2007

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The New York Times

The DNA Age

Cancer Free at 33, but Weighing a Mastectomy

Deborah Lindner, 33, did intensive research as she considered having a preventive mastectomy after a DNA test.

By AMY HARMON
Published: September 16, 2007

CHICAGO — Her latest mammogram was clean. But Deborah Lindner, 33, was tired of constantly looking for the lump.

Ever since a DNA test had revealed her unusually high chance of developing breast cancer, Ms. Lindner had agonized over whether to have a mastectomy, a procedure that would reduce her risk by 90 percent.

She had stared at herself in the mirror, imagining the loss of her familiar shape. She had wondered, unable to ask, how the man she had just started dating would feel about breasts that were surgically reconstructed, incapable of feeling his touch or nursing his children.

But she was sure that her own mother, who had had chemotherapy and a mastectomy after a bout with the cancer that had ravaged generations of her family, would agree it was necessary.

For full article: http://www.nytimes.com/2007/09/16/health/16gene.html?_r=1&oref=slogin

Joanna's decision

A Chicago woman turns her fate into film. By **Rachelle Treiber**

Imagine finding out that you carry a genetic mutation that greatly increases your risk of developing breast or ovarian cancer in your lifetime. Now imagine getting the news at the age of 27.

That is what happened to Chicago resident Joanna Rudnick nearly five years ago. Now, at 32, Joanna is making a documentary film about her journey to decide what to do after testing positive for the BRCA1 gene – the genetic test for hereditary breast and ovarian cancer. The film is called *In the Family* and is being made through Chicago-based Kartemquin Films, of *Hoop Dream* fame. The documentary is set for completion next year.

"This is not a film that is pro- or anti-genetic testing, but rather an exploration of the women living with this decision and their right to decide what is best for them," said Joanna, who has worked at Kartemquin for several years. "I really wanted to tell this story to help prepare other women."

Although the stories of many women are documented in the film, Joanna's story begins with her mother's diagnosis of fallopian tube cancer – a form of ovarian cancer – at age 43. Joanna was 13 at the time. Doctors caught it early, and her mother survived.

Risk awareness

Joanna's older sister, a mammographer, always knew the red flag was raised in terms of cancer risk, so she entered into an early detection program. While anyone can get tested, if you have a person alive in your family who had cancer that is the person to test, Joanna said.

"Not everyone who had cancer will test positive for BRCA," she said. "My mother got tested for every mutation and came up positive for the BRCA1 mutation. Then my sister tested, and she was negative."

I didn't even question whether to test. I jumped right into it thinking, 'If you could know, why not?'" Joanna said.

Upon hearing her fate, she was faced with the overwhelming decision of whether to schedule surgery to remove her ovaries and breasts. "I was so unprepared to hear that," said Joanna. "I was used to going to a doctor, having a problem, and they tell you how to fix it. Instead, I was told to make the decision about getting rid of my ovaries or breasts."

After careful consideration, she chose surveillance. Joanna says the decision was based on more than just her wish to have kids someday. "This is when breast MRI's became available, which is a much better screening process. I made a deal with myself that I could live with the knowledge that I had this mutation because I knew I couldn't stop it, but I knew I could catch it early."

For now, Joanna gets regular MRI high-risk screenings at Rush University Medical Center's Breast Imaging Center. She is still surprised to be telling her story. "It took so long to be comfortable with this," she said. "But I want to raise awareness because the key to curing cancer could be in this hereditary population."

Joanna said she cannot stress enough the importance of genetic counseling. In addition to counselors, there is a support group (see box) for women who have tested positive for these genetic mutations.

Joanna gets regular MRI high-risk screenings at Rush University Medical Center.

further information

For more information on the support group, go to www.facingourrisk.org. To watch for information on *In the Family* visit www.kartemquin.com.

CHICAGO SUN-TIMES

Why no one is cutting off my breasts

BY KIRSTEN MILLER
October 4, 2007

I had my first mammogram at 23—a year after I found out my mother had Stage 4 breast cancer.

The doctor at Swedish Medical Center in Seattle argued that I was too young. But I insisted. Not only had my mom's mother battled the disease about 15 years earlier, but my younger sister also had already had a noncancerous lump removed from one of her breasts.

I was determined to do anything I could to keep myself from getting the disease I watched terrorize my family.

But that was before prophylactic bilateral mastectomies—removing both of a person's cancer-free breasts with prevention in mind—became mainstream.

That, I would never do.

Lately, it seems I can't turn on the TV or open the paper without hearing about a young woman who has opted to have this done. It makes my stomach turn.

Kirsten Miller with a photo of her grandmother, Laurine Mitchell, who died of breast cancer at age 81. (Jean Lachat)

Just a couple of weeks ago, the New York Times chronicled Deborah Lindner's decision to lop off her breasts, based on a strong family history of breast cancer and DNA testing that showed she had a high chance of developing the disease.

Lindner, a 33-year-old Chicago woman, underwent genetic testing to see if she had mutations in two of the four known breast-cancer genes—BRCA1 or BRCA2. Mutations in those tumor-suppressing genes are linked to inherited forms of breast and ovarian cancer.

I respect her decision. Genetically inherited breast cancer typically comes on before age 50 and once it's in one breast, it's more likely to occur in the other. What's more, half of the women who test positive for BRCA1 get ovarian cancer, a disease that's fatal 75 percent of the time because it can't be diagnosed early. Only 2 percent of the general population of women get ovarian cancer.

But I wouldn't follow suit if I were to test positive for one of the gene mutations.

For full article: http://www.suntimes.com/news/otherviews/587814,CST-NWS-contro04.article

Chicago
October 2007

The Deadly Difference

BY SHANE TRITSCH

Black women in Chicago are far likelier to die of breast cancer than white women, resulting in a disparity that's nearly double what it is nationally. This pattern of racial inequality shows up locally with other diseases—evidence that Chicago is failing at narrowing its racial divide in health. Why? And what must be done?

"I'm tired of saying goodbye to women who should still be here," says Martha Haley, who is battling breast cancer.

Whenever breast cancer claims the life of another friend, Martha Haley inscribes the woman's name and date of passing in a special book of remembrance. Haley, who's waging her own tough fight against the disease, started compiling the book to honor the memory of women she came to know through Celebrating Life, the support group she founded a decade ago for African Americans who, like herself, have been diagnosed with breast cancer. The book is thick with photographs of the dead and with the poems and tributes Haley has composed to commemorate their lives. "I bonded with these women of color, and I watched them lose their battle," she says. "It's *hard* knowing and loving people and then saying goodbye."

For full article: www.chicagomag.com/Chicago-Magazine/October-2007/The-Deadly-Difference/

WSJ.com THE WALL STREET JOURNAL. ONLINE

Ad Campaign Fuels Debate On Breast-Cancer Gene Test

Critics Say Calling Attention to a Rare Risk Factor May Create Unnecessary Fear

By MARILYN CHASE

September 11, 2007; Page D1

A new direct-to-consumer ad campaign for a breast-cancer gene test is reigniting a debate over who really needs the test and whether it will induce low-risk women to take drastic measures to prevent the disease.

At issue is a series of ads to promote Myriad Genetics Inc.'s test for so-called BRCA 1 and BRCA 2 gene mutations. The mutations, while rare, signal a high risk of developing breast or ovarian cancer in affected women. Women who find they carry the mutations often take steps to lessen their risk. That can mean more frequent screenings and taking certain preventive drugs, but also can include prophylactic surgical removal of a woman's breasts or ovaries.

The gene tests aren't foolproof, however. And some experts worry that a campaign calling attention to a rare condition could create unnecessary fear -- sending thousands of healthy women with no family history of cancer into the doctor's office demanding tests that won't help them. Or lead others to a false sense of security about their results.

"Marketing has the capacity to raise public awareness -- a good thing," says Alan Guttmacher, deputy director of the National Human Genome Research Institute, a unit of the National Institutes of Health in Bethesda, Md. But "with BRCA 1 and 2, people can get uncertain test results. What do you do with that information?"

In Salt Lake City, Gregory Critchfield, president of Myriad Genetic Laboratories Inc., Myriad's gene-testing unit, says the company vetted the awareness campaign with insurance companies and shared it with medical experts and government officials at the NIH. "We are confident that our materials represent the highest quality of information," he says. Dr. Guttmacher said his institute hasn't taken any official position on the test.

Television commercials hit the airwaves yesterday in New York City; Boston; Hartford, Conn.; and Providence, R.I., as part of a multimedia blitz aimed at promoting awareness and use of Myriad's test.

For full article: http://online.wsj.com/public/article/SB118946587203223125.html

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