

# KARTEMQUIN FILMS PRESENTS



# ON BEAUTY

**A film by Joanna Rudnick**

31 minutes

**Official Selection**

**2014 Chicago International Film Festival - audience award, best short film**

2014 Hot Springs Documentary Film Festival

2014 Rocky Mountain Women's Film Festival

2014 DOC NYC

2015 Big Sky Documentary Film Festival

2015 ReelAbilities Film Festival - Cincinnati, Houston, New York

**2015 Geneva Film Festival - best documentary short**

**2015 Cleveland International Film Festival - jury prize, best documentary short**

**2015 Sebastopol Documentary Film Festival - audience award**

**Publicity Contact**

Kartemquin Films

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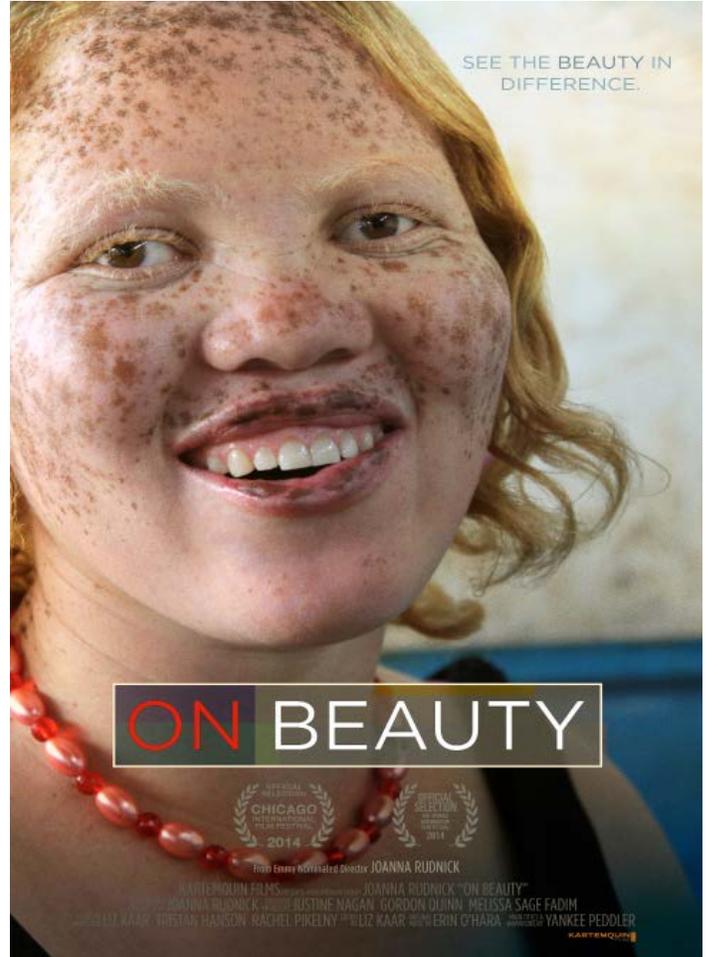
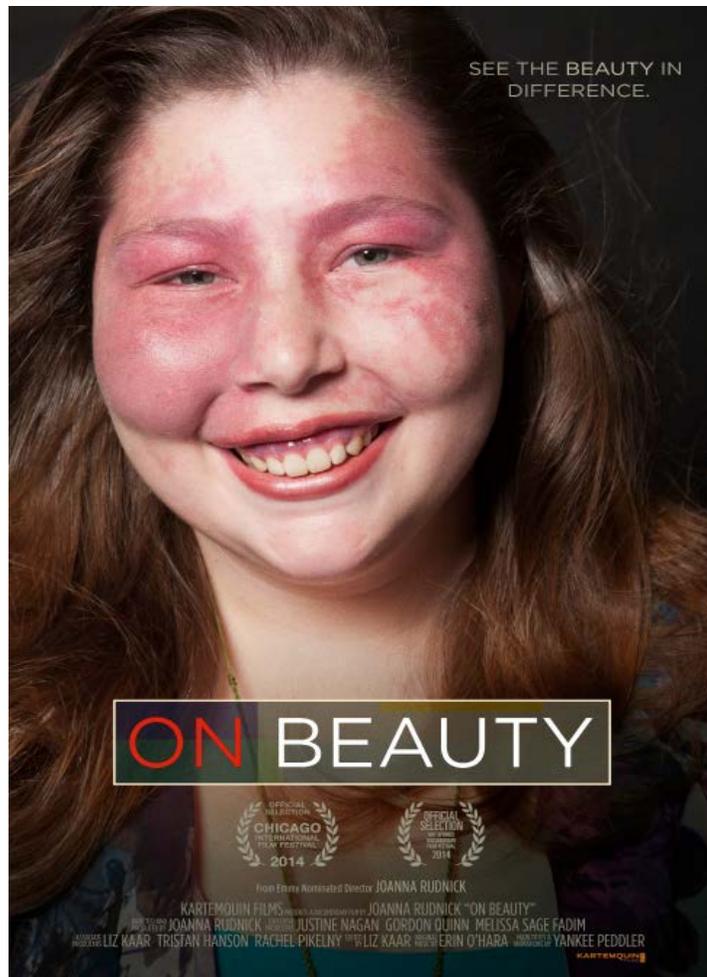
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# SYNOPSIS

From Emmy-nominated “In The Family” filmmaker Joanna Rudnick and Chicago’s Kartemquin Films comes a story about challenging norms and redefining beauty. ON BEAUTY follows fashion photographer Rick Guidotti, who left the fashion world when he grew frustrated with having to work within the restrictive parameters of the industry’s standard of beauty. After a chance encounter with a young woman who had the genetic condition albinism, Rick re-focused his lens and uses it to challenge convention and redefine beauty with the help of two extraordinary women.



At the center of ON BEAUTY are two of Rick’s photo subjects: Sarah and Jayne. Sarah left public school for home school in eighth grade because she was bullied so harshly for the Sturge-Weber birthmark on her face. Jayne lives in Eastern Africa where people with albinism are highly discriminated against and are sometimes even killed for their body parts. Rick’s photos challenge both mainstream media’s narrow scope of beauty and the dehumanizing black-bar convention of medical textbooks. ON BEAUTY is part of his movement.

## ABOUT THE FILM

ON BEAUTY is the latest film from award-winning filmmaker Joanna Rudnick and Chicago's [Kartemquin Films](#). The film looks at beauty through the lens of fashion photographer Rick Guidotti, who highlights vibrant individuals with genetic conditions. His photographs are a stark contrast to the sad, isolated figures seen in medical textbooks and they inspire many to change their public perceptions on what it means to be beautiful.

Rick had a successful career in New York, Milan and Paris and worked for clients such as Elle, Harper's Bazaar and Yves Saint Laurent. He grew frustrated with having to work within the industry's restrictive standards of beauty. One day in New York, he had a chance meeting with a stunning young woman who had albinism. He was immediately struck by her beauty and researched the genetic condition.

What he found in medical textbooks were depressing images with dehumanizing black bars covering the person's eyes. He partnered with the National Organization for Albinism and Hypopigmentation to create a set of photos that highlighted the individual not the disease. His photos appeared in Life Magazine in June 1998. Soon after he created a foundation built on his mission called [Positive Exposure](#).

Joanna first saw Rick's stunning photographs at a Genetic Alliance conference in 2009 where she was presenting her directorial debut film, "In the Family." She was speaking about her own experience with having an unseen genetic condition and began to think about what it would be like to have a condition that made you visibly different.

For the past five years, Joanna has followed Rick around the world, from his studio in New York City to conference halls in Las Vegas to a remote village in Kenya. At the center of the film are two people he meets along the way: Sarah Kanney and Jayne Waithera.

Sarah was born with Sturge-Weber syndrome, a condition that leaves a port wine birthmark on her face and brain. Since she was four, she has needed multiple eye surgeries, but it hasn't deterred her from her passion -- racing motocross. Sarah said when she puts on her helmet she feels free from the stares and judgments from others. When she was in eighth grade Sarah was bullied so harshly she left

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"I can assure you that **no one** has ever walked into a doctor's office ... carrying a portable **black bar**"

— Rick Guidotti

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public school for home school. Her meeting with Rick helped Sarah gain independence and confidence. She got a job, moved out on her own and started to study for her GED.

Jayne was raised by her grandmother after her mother abandoned her, a common occurrence for people with albinism in Eastern Africa. The society does not understand the specific health and safety needs. They are called "money" or "walking banknotes" because witch doctors will pay for their body parts. Jayne was researching albinism when she came across Rick and his work. Immediately she knew she had to meet him. She has grown into a leader in her community and helped found the first Positive Exposure branch in Kenya.

Rick, Sarah and Jayne help us recognize the limitations of dismissing people who are different and their experiences will motivate people to change public perceptions.



# DIRECTOR'S STATEMENT – JOANNA RUDNICK

It's the image that never leaves my mind – a young girl with crooked glasses and a bottomless smirk looking directly at me from the canvas. She is having a blast, and I want in to her world. I want to know her. Never once in the hundreds of times I've stared at her face have I thought about illness, difference, syndrome, genetics, faulty chromosomes or limitations. She's a kid having fun and her name is Pauline.

This is the gift of Rick Guidotti, who, in my mind, is a prophet of our time. Rick has some incredible filter that cuts through all of the negativity, stigma, prejudice and isolation of difference. He gives us the space, permission and tools to see people as he sees them and how they want to be seen – whether you're a supermodel, his first photos subjects, or a child with a genetic syndrome.

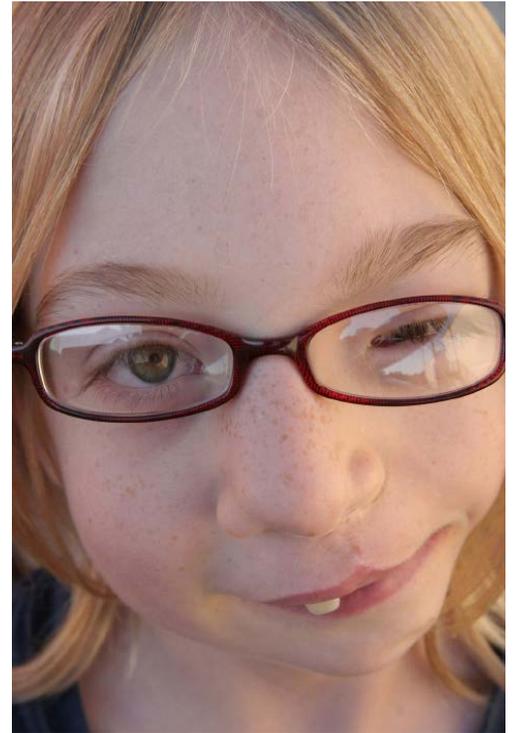
I first encountered Rick's work at the Genetic Alliance conference in 2009. I was there screening my first film, "In the Family" (Kartemquin Films, POV – 2008). I spent the weekend speaking about my unseen genetic condition and was stuck by what it must be like to live with a genetic change that was visible to the rest of the world. How are you treated differently? What are the consequences? What are the solutions?

As many of us are, when I have encountered photography of people with genetic syndromes, my association was dehumanizing black-bar photographs that isolate and highlight difference. Rick's photography was an exact affront to that imagery, allowing people to have names, larger-than-life personalities and identities outside of one defining label.

I asked Rick if I could follow him around for a documentary and it turned into a five-year journey from Las Vegas to Kenya and places in between. What I learned along the way, I can't summarize here, but I hope you will feel it when you watch the film. The image that stands out to me is Judy Kanney's response to seeing her daughter Sarah Kanney, who has Sturge-Webber Syndrome, photographed by Rick for the first time – a smile and sense of pride I'd never witnessed before. And seeing the resulting poise straighten Sarah's posture as she liked out with confidence addressing a full auditorium of high school students, after leaving high school for homeschooling because of bullying.

I wish we could all see like Rick. As Rick's friend the prominent fashion designer Ralph Rucci said, Rick is like an anthropologist way ahead of his time. Let's catch up to him!

Joanna Rudnick  
Director/Producer  
ON BEAUTY 2014  
Kartemquin Films



# FILMMAKERS

## Joanna Rudnick, director/producer



Director/producer Joanna Rudnick has been a documentary filmmaking associate with Kartemquin Films for more than a decade. She most recently directed an episode of “Hard Earned,” a six-part television series following the lives of hard-working Americans produced by Kartemquin for Al Jazeera America. Joanna was the supervising producer on the HBO film “Crossfire Hurricane,” which chronicled 50 years of the Rolling Stones.

Joanna’s directorial debut, “In the Family,” was nominated for the 2009 Emmy Award for Outstanding Informational Programming—Long Form. The film is about her personal journey after she learned she had a genetic condition that significantly increased her chances to develop breast and ovarian cancers.

“In the Family” premiered at SILVERDOCS in 2008, was broadcast nationally on PBS’ P.O.V. series and internationally in a dozen countries. It was a finalist for the NIHCM Foundation’s Health Care Radio and Television Journalism Award. Through her work on “In the Family,” Joanna lobbied for the passage of the Genetic Information Nondiscrimination Act and was an early proponent of challenging the patent on the BRCA genes.

Joanna produced Kartemquin’s “Prisoner of Her Past,” the story of a Holocaust survivor who relives her traumatic childhood in a state of late onset PTSD, which was broadcast on PBS in 2011. She also produced “A Good Man,” the story of the creation of a major dance theatre piece on Abraham Lincoln by choreographer Bill T. Jones.

Before coming to Kartemquin, Joanna enjoyed a fruitful tenure with the AMERICAN MASTERS series at WNET (PBS) in New York, co-producing “Robert Capa in Love and War,” which broadcast on PBS and the BBC. “Capa” was a selected film at the 2003 Sundance Film Festival and was the presenting film for the 2003 Emmy Award for Outstanding Nonfiction Series. Joanna holds a master’s degree from NYU in science and environmental journalism and a bachelor’s degree from Northwestern University.

## Gordon Quinn, executive producer



Kartemquin Films founding member Gordon Quinn has been making documentaries for more than 45 years and currently serves as the company’s artistic director. Gordon helped create a legacy that inspires young filmmakers and provides a home where they can make films that investigate and critique society.

Gordon is an executive producer on every new Kartemquin film, lending his wisdom, experience and artistic vision to each. He is a leader in advocating for fair-use and is also a founding member of the Indie Caucus – a national independent group of filmmakers who support the public mission of public media.

**Justine Nagan, executive producer**

Justine is the executive director of Kartemquin Films, and is the executive producer for many of the production company's current works. She directed the Kartemquin film "Typeface" (2009) and was an associate producer on the 2009 Peabody Award winner "Mapping Stem Cell Research: Terra Incognita" (2007). She also helped Kartemquin develop an education series while earning a master's degree in humanities from the University of Chicago.

She has experience as a teacher at the Hyde Park Art Center, a theatre manager for the Chicago International Film Festival and a fellow for The HistoryMakers. Before moving to Chicago, she produced promotional spots for public television and worked for various companies including M&C Saatchi Australia and Michael Feldman's "Whad'Ya Know?" on National Public Radio.

**Melissa Sage Fadim, executive producer**

Melissa Sage Fadim is the creator and executive producer of the documentary series "Islands Without Cars." This unique series offers viewers the opportunity to experience islands around the world that operate outside of the frantic pace of modern urban life and provides the opportunity to travel back in time. The series was written and produced by three-time Chicago Emmy winner Terry Spencer Hesser. Melissa is also the executive producer of the acclaimed documentary "Raising the Barre: The Homer Bryant Story" (2009).

**Liz Kaar, editor/associate producer**

Liz Kaar is an independent filmmaker with a storied history at Kartemquin Films. Currently she is one of the editors for "Hard Earned," Kartemquin's new six-part series for Al Jazeera America about hard-working Americans.

From 2008 to 2012 she served as the director of post production and edited Justine Nagan's documentary "Typeface" (2009). She was the assistant editor on "No Crossover" (2010), "Milking the Rhino" (2008) and Joanna Rudnick's directorial debut, "In The Family" (2008). She has worked as one of the producers for some of Kartemquin's recent DVD releases, including "Home for Life" and "The New Americans."

In addition to her work at Kartemquin, she is editing the new documentary "Andrew Bird: Fever Year" and directing a documentary short about the opening of the first vegan takeout restaurant in Chicago.

# USEFUL INFORMATION



## **A note about referring to people with genetic conditions:**

When referring to people with any disease or disability put the person first, then the condition second. For example: “a person with albinism,” not “an albino.” Many people consider “albino” a derogatory term.

## **DNA, genes and chromosomes**

DNA is the hereditary material that acts as an instruction manual for creating and maintaining an organism. DNA is located in cells and arranged in a double helix structure, which makes duplication efficient and accurate.

Genes are specific sections of DNA that contain instructions on how to make proteins and how those proteins will function. These instructions can give humans hereditary traits such as eye color and skin tone. Most humans have two copies of each gene, one from each parent and genes can be turned on and off, which is called gene regulation.

The strands of DNA are tightly packed into structures called chromosomes. Humans normally have 23 pairs of chromosomes, for a total of 46. All but one of these pairs are the same in both males and females. The last pair, called the sex chromosome, is different in each gender where males have an X and Y, and females have two Xs.

## **Genetic disorders**

Permanent gene mutations are called genetic disorders. Most genetic mutations have little or no impact on a person’s health and development, and there are many ways a cell can check for and repair abnormal genes. Genetic mutations that inhibit essential cell function can cause diseases. Genetic disorders can be inherited from the parents or as a result from external environmental factors.

## 25 to 30 million Americans are living with a rare disease

Examples of genetic disorders include:

- an extra copy of a chromosome (Down syndrome, usually chromosome 21)
- loss of a chromosome (Turner syndrome)
- deletion of chromosomes (Williams-Beuren syndrome)

Rare diseases are defined as conditions that affect fewer than 200,000 people, and 80 percent of rare diseases are caused by genetic disorders. There are more than 6,800 rare diseases and an estimated 350 million people live with a rare disease worldwide. In the United States, the estimate is from 25 to 30 million people, which is about 1 in 10 Americans.

For more information visit: <http://ghr.nlm.nih.gov/handbook/>





### **Sturge-Weber syndrome**

Sturge-Weber syndrome is a disorder of unknown origin characterized by a port-wine birthmark on the face. The birthmark is also on the brain, which can sometimes cause neurological abnormalities. The rarity of the condition makes it difficult to track how many people are living with Sturge-Weber syndrome. Estimates of the total number of affected people range from one in 400,000 to one in 40,000.

For more information visit: <http://www.sturge-weber.org>

### **Albinism**

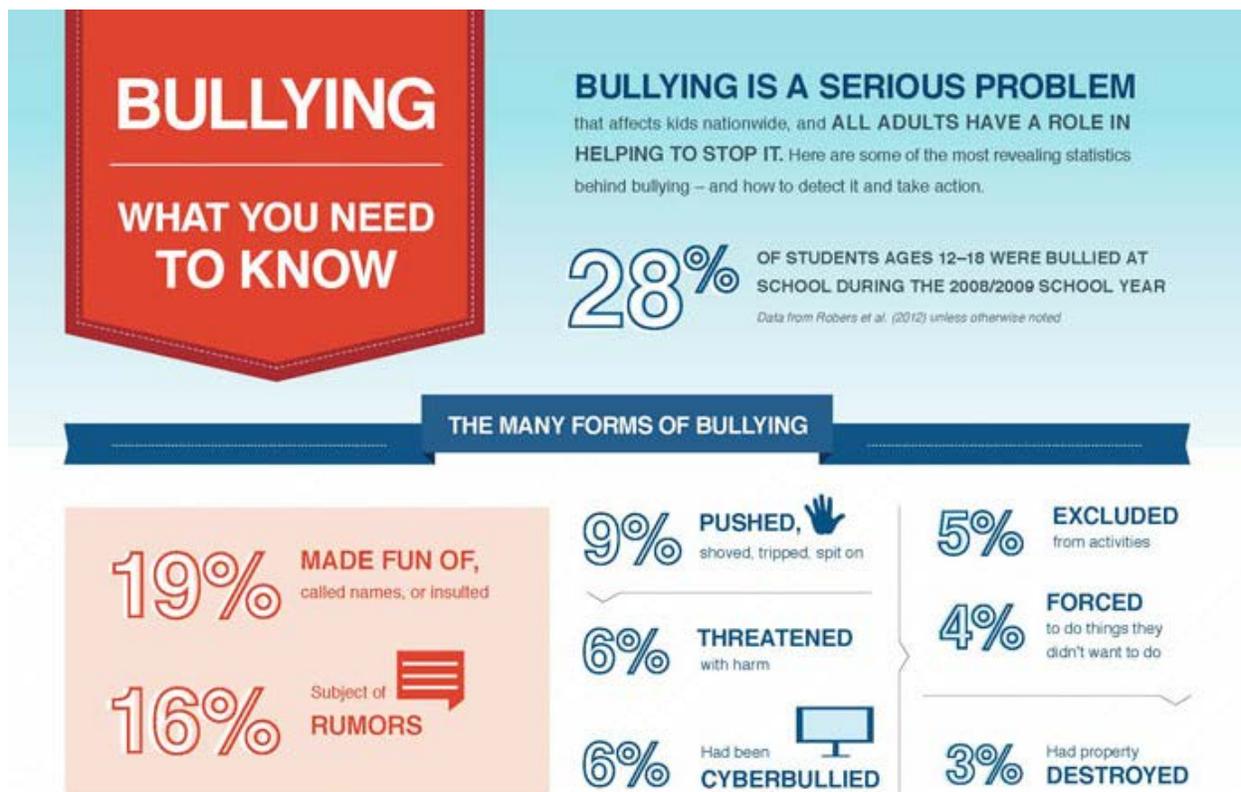
Albinism is an inherited condition results little or no pigment in the eyes, skin and or hair. People with albinism have can have a variety of traits, but all have some vision problems, many of who are legally blind. About one in 17,000 people in the United States has albinism. Albinism is a recessive trait, which means both parents must pass the mutated gene to their child.

For more information visit: <http://www.albinism.org>

**Bullying**

The site [www.stopbullying.gov](http://www.stopbullying.gov) defines bullying as “unwanted, aggressive behavior among school aged children that involves a real or perceived power imbalance.” It can be online, verbal, social or physical. Bullying is harmful to every one involved from those who have been bullied to those who bully and those who have witnessed bullying. Both kids who are bullied and kids who bully are more likely to have depressive symptoms and attempt suicide.

According to the National Center for Education Statistics, about 28 percent of students aged 12-18 years old said they were bullied during the 2011 school year. Bullying often goes unreported, and 47 percent of 12 graders said they never told anyone about a bullying incident. Forms of bullying include name-calling, purposefully leaving someone out of a group, spreading rumors, threats, destruction of personal property and physical attacks.



Infographic from [www.stopbullying.gov](http://www.stopbullying.gov)

## INTERVIEW SUBJECTS

- Sarah Kanney – young woman with Sturge-Weber syndrome
- Jayne Waithera – young woman with albinism
- Rick Guidotti – fashion photographer, founder of Positive Exposure
- Judy Kanney – Sarah Kanney’s mother
- Dave Kanney – Sarah Kanney’s father
- Diane McLean – former co-director of Positive Exposure
- Jane Waithera Kiago – Jayne Waithera’s grandmother
- Tabitha Wangui Kiago – Jayne Waithera’s great-grandmother
- Margaret Breed – young woman with albinism who inspired Rick to leave the fashion industry
- Joseph Boggess – hair and makeup artist
- Isolde Motley - Former editor of Life Magazine
- Alisha & Emarie – mother and daughter at chromosome 18 conference
- Jenny & Deacon – mother and son at chromosome 18 conference
- Stanley B. Burns, M.D. – creator and curator at Burns Archive



# TECHNICAL CREDITS



Directed and produced by  
Joanna Rudnick

Editor  
Liz Kaar

Executive producers  
Justine Nagan  
Gordon Quinn  
Melissa Sage Fadim

Main titles & animation by  
Yankee Peddler

Original music by  
Erin O'Hara

Associate producers  
Liz Kaar  
Tristan Hanson  
Rachel Pikely

Camera  
Dana Kupper  
Jerry Risius

Sound recordists  
Judy Karp  
John Mathie

Sound edit and mix  
Philip Perkins

Colorist  
Ayumi Ashley

Assistant editor &  
post production supervisor  
Will Thwaites

Technical Supervisor  
Jim Morrissette

# ABOUT KARTEMQUIN

Kartemquin Films is a collaborative center for documentary media makers who seek to foster a more engaged and empowered society. With a noted tradition of nurturing emerging talent and acting as a leading voice for independent media, Kartemquin is building on more than 48 years of being Chicago's documentary powerhouse.

Kartemquin sparks democracy through documentary. Their films, such as "The Interrupters," "Hoop Dreams" and "The New Americans" have left a lasting impact on millions of viewers. A revered resource within the film community on issues of fair use, ethics, story and civic discourse, Kartemquin is internationally recognized for crafting quality documentaries backed by audience and community engagement strategies and for its innovative media arts community programs.

Kartemquin is a 501(c)3 not-for-profit organization.

[www.kartemquin.com](http://www.kartemquin.com)