

Overview

"On Beauty" is not just a film, but a call to action for people to change the way we see and treat one another. The "On Beauty" education initiative focuses on engaging young people in the conversation and empowering them to advance the movement.

This kit contains background information, useful external links and the lesson plan to teach students about genetics, bullying and the value of diversity. Students can also get involved in our **"Beauty in Difference"** gallery — a safe and constructive forum for people to share their experiences and discuss the diversity of beauty.



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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 working 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 the condition albinism. He was immediately struck by her beauty and soon left the fashion world.

He then completed a photo series of people with albinism that ran in Life Magazine. After the article was published, Rick began to get numerous requests from parents from all around the world asking him to meet and photograph their children. A foundation that supports people affected by chromosome 18 mutations asked him to attend their conference. Soon after he created Positive Exposure, the foundation based on his mission.

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 the rest of the world can immediately notice. For the past five years, she has followed Rick around the world from his studio in New York City to a conference 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. She 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 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 because her mother abandoned Jayne for having albinism. In Eastern Africa, the society is often blind to the specific health and safety needs for people with the genetic condition. They are called “money” or “walking banknotes” because witch doctors will pay for their body parts. While researching albinism she came across Rick and 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 helps reveal the limitations of current public perceptions, and more importantly emphasizes the person not the condition. ON BEAUTY will help advance his movement and change the way we see and experience beauty.

Background information

Genetics

Cells are the building blocks of all living organisms. They provide structure, carry out essential functions for life and contain DNA, the body’s hereditary material. Half of a person’s DNA comes from the mother, the other half comes from the father. It is made up of four chemical bases (A, T, C and G), which form base pairs in a double helix structure.

Genes are groups of DNA that provide the body with instructions on how to make essential protein molecules. Chromosomes are sets of tightly-wound DNA located mostly in a cell’s nucleus. Humans normally have 23 pairs of chromosomes, 22 of which are the same in both genders. The last pair is called the sex chromosome because females have two Xs and males have an X and a Y. In the lab, scientists often stain chromosomes with chemicals to reveal bands that indicate the location of genes.

Genetic mutations are permanent changes to the DNA sequence in a gene that can be inherited from the parents or develop during a person’s lifetime such as from environmental factors or when there is a mistake during DNA replication. Genetic conditions occur when one or more mutations prevent proteins from functioning properly, which can lead to developmental and health issues. Many genetic mutations do not cause health problems and genetic alterations can be responsible for eye color, hair color and blood type. This can make it difficult to precisely diagnose genetic conditions that adversely affect a person’s health.

There are many types of genetic mutations, including:

- Missense: Change in one DNA base pair where an amino acid replaces another protein produced by a gene
- Nonsense: Change in one DNA base pair where altered DNA prematurely signals to stop building a protein and can lead to function improperly or not at all
- Insertion: Adds a base pair to a piece of DNA and protein may not function or function improperly
- Deletion: Removes piece of DNA, can range from small number of DNA base pairs to whole genes
- Duplication: Piece of DNA abnormally copied one or more times

There are now more than 7,000 rare diseases and genetic mutations are a factor for significant portion of them. Rare diseases affect about 1 in 10 Americans, or about 30 million people nationwide, and about 350 million people worldwide. About 80 percent of rare diseases are caused by genetic mutations. Researchers have made progress in understanding genes since the Human Genome Project completed the map of the human genome sequence in 2003, but there is still much to learn about genetics.

Bullying

The U.S. government site StopBullying.gov defines bullying as “unwanted, aggressive behavior among school aged children that involves a real or perceived power imbalance. The behavior is repeated, or has the potential to be repeated, over time.”

About 28 percent of students from age 12-18 years old said they were bullied in the 2011 school year. Forms of bullying include name-calling, purposefully leaving someone out of a group, spreading rumors, threats, destruction of personal property and physical attacks.

Educators, parents and adults can help by talking directly to kids about bullying and providing support http://iambeauty.me/wp-admin/edit.php?post_type=shop_order to all those involved. It is important to know that bullying can negatively impact kids who are bullied and kids who bully.

Issues in Eastern Africa

Many people with albinism in Eastern Africa constantly live in fear of being mutilated or killed because area witch doctors will pay tens of thousands of dollars for their body parts. This issue is most highly concentrated in Tanzania and overflows into Burundi, Malawi and even Jayne's home country of Kenya.

The United Nations estimates about 74 people with albinism have been killed in Tanzania since 2000. Jayne said there is often an increase in attacks during elections because many politicians believe body parts from people with albinism have the power to bring good luck. In January 2015, the Tanzanian government banned witchdoctors and arrested more than 200 in attempt to stop the recent surge. While this may help, organizations such as Positive Exposure Kenya continue to work at educating people and changing how the culture sees people with this genetic difference.

Diversity in media

Representations of beauty in the media continue to change, and recently many organizations and outlets have included more diverse people in their campaigns. Adam Pearson tackled stigmas when the young actor, whose face is covered in tumors from neurofibromatosis, starred alongside Scarlett Johansson in the 2013 film “Under the Skin.” In 2014 psychologist Dr. Danielle Sheypuk, who lives with spinal muscular atrophy, became the first person in a wheelchair to model on the runway at NY Fashion Week. A year later actress Jamie Brewer became the first person with Down syndrome model during the event. In 2013 a Swiss organization showcased mannequins modeled from real people with various disabilities in a Zurich storefront. The next year J.C. Penny revealed a similar campaign in its Manhattan location. Tess Holliday, the tattoo-covered size-22 model who started the #effyourbeautystandards hashtag, became the first of her size to sign with a major modelling agency.

These cases are inspiring, but far from being the norm. Fashion magazine covers rarely show people of diverse physical appearances. “The Fashion Spot” blog looked at 44 of the world's leading fashion publications and analyzed their covers from 2014. They found only 19 percent of the people on the covers were non-white models. The annual TV report from GLAAD showed that while the U.S. Census estimates about 12 percent of Americans live with a disability, only about 1.4 percent of primetime television characters for the upcoming season will have a disability.

The problems not only come from the lack of representation, but also how people are represented and included in the process. In 2012 the BBC examined the roles that won leading actor and actress an Oscar. Tied for first, at 16 percent, was playing someone with a mental illness or physical disability. While such high-profile portrayals can have a positive impact, some people such as Pearson also want to see industries include people in the productions, not just represent them.

For more examples that challenge current conventions, reference the external resources or our [“Beauty in Difference”](#) gallery.

Discussion Guide

Name: _____ Date: _____

1. How do major media outlets commonly represent beauty? Use examples from the film and other sources such as magazines, television shows, films and literature.
2. How are people with medical conditions commonly represented in media and medical textbooks? Use examples from the film and other sources.
3. How do Rick's photographs challenge these representations of beauty and people with genetic conditions?
4. What obstacles do Jayne and Sarah face for being physically different? Which obstacles are the same, which are different?
5. How did Sarah and Jayne overcome the obstacles they faced?

Lesson Plan

Objectives

At the end of the lesson, students will be able to:

- Identify what can influence definitions of beauty
- Understand that perspectives are diverse and ever-changing
- Express their personal definitions of beauty and apply this to themselves and others

Grade Levels

9 - 12

Subjects

Health, biology, language arts, arts, current events

Estimated time to complete

Two 50-minute class periods or one 90-minute class period and additional time to complete personal project.

DAY 1

Materials

"On Beauty" film and "On Beauty" discussion guide

Activity

- Set up film: Ask students to write how they would define beauty and give examples of people who fit their definition. Have some students share their definitions and examples. Point out that each person may have a different definition.
- Show the film and then have students complete the discussion guide.
- Closure: Ask students to think about how they would revise their definitions of beauty in preparation for the personal paper they will write.

Assessment

Responses to study guide questions; contributions and participation in class discussion.

DAY 2

Materials

Examples of how people with differences are commonly represented in the media and medical text books and examples that challenge these norms. Refer to background information and external resources for examples.

Activity

- Show students examples of beauty from a variety of sources, including from magazines, TV shows, movies or our **"Beauty in Difference"** gallery. Ask students to describe the physical attributes of the people in the photographs and their emotional responses to the images.
- Ask students: Are there any common characteristics found in every one of these examples? Does every student react the same to each example?
- Ask students to discuss how they believe their society defines beauty and if there is a universal definition of beauty
- Rick Guidotti's photographs appeared in "Life Magazine" in June 1998. Ask students: How have society's representations of beauty and people with genetic conditions changed and/or remained the same since then?
- The U.S. Census estimates about 19 percent of the American population live with a disability. A study by GLAAD found that in 2014 only 1.4 percent of regular characters on scripted broadcast TV have a disability. Ask students how they think television, film, magazines, music and other media impact societal and personal perceptions. Ask students to discuss how more frequent and more diverse representations of beauty could change perspectives.
- Closure: Have students write down how their definition of beauty changed after seeing the film. Ask students discuss what viewpoints did or did not change and why. Have students begin writing their personal papers.

Out-of-class assignment

Write a paper about how to define beauty that draws from the film, class discussions and outside sources. The paper should have three parts:

- Your personal definition of beauty and what factors you believe contribute to your definition.
- An example of someone you personally know who you consider beautiful and an explanation as to how this person fits in your definition.
- A description of what makes you different from your peers and how this difference fits into your definition of beauty.

Assessment

Contributions and participation in class discussion; how well the student recognized and interpreted themes from the film; how well the student applied writing skills to the personal paper.

OPTIONAL EXTENSIONS

Have students create a project that represents their definition of beauty. Students can use any medium including: creative writing, poetry, photography, painting, collage, performing art, etc. Have students share their projects with the class and write a one-page paper that explains how this project shows the way they see beauty. Ask students to also include a description of what they think makes them beautiful. Students can also share their projects online at our **"Beauty in Difference"** gallery.

External Resources

Organizations

Challenging perceptions

- **Positive Exposure** - Rick Guidotti started the foundation in 1998 to use his photographs to transform the way we see and treat people's differences
- **PEARLS Project** - Positive Exposure's interactive educational tool that gives students a "deeper understanding and respect for human diversity"
- **The Honest Beauty Project** - Facebook campaign started by two high school girls that shows the many sizes of beauty

General Genetics

- **Genetic Alliance** - A worldwide leader in health advocacy that focuses on genetics, but uses a multidisciplinary approach to improve health
- **American Society of Human Genetics** - Professional organization for human genetics specialists that uses research, education and advocacy
- **Global Genes** - An advocacy group to support people affected by the challenges of having a rare disease

For specific genetic conditions

- **NOAH** - National Organization for Albinism and Hypopigmentation
- **Sturge-Weber Foundation**
- **Marfan Foundation**
- **Chromosome 18 Registry & Research Society**

Bully prevention

- **StopBullying.gov** – Website with information and resources to help curb bullying that is managed by the U.S. Department of Health and Human Services
- **National Association of Elementary School Principals** – Bullying prevention resources and tools for elementary educators
- **CDC bullying research** – Research and resources collected by the Centers for Disease Control and Prevention

Diversity in Media

- **"How to win an Oscar"** (BBC) – Article that examined what types of roles won best actor/actress Oscars (person with mental illness or disease tied for first)
- **Where We Are Now on TV report 2014** (GLAAD) – Annual report from Gay & Lesbian Alliance Against Defamation that surveys diversity on primetime television
- **National Center on Disability and Journalism** – Center to support and guide journalists who cover people with disabilities with headquarters at Arizona State University
- **Diversity Report from "The Fashion Spot"** – Examination of the diversity of fashion magazine covers from 2014

Beauty in difference examples

Articles, videos and other examples of diverse representations of beauty in the media. Also visit the **"Beauty in Difference"** gallery online.

- **Axis Dance Company** – Dance company founded in 1987 that incorporates dancers with and without disability through performances and outreach education
- **Rick and Dick Hoyt** (ABC News)- An athletic duo of Rick, who was diagnosed with cerebral palsy when he was born, and his father who pushes him to the finish line of some of the world's toughest races
- **Michaela DePrince** (CNN) – Once an orphan in Sierra Leone who was shunned for the vitiligo that caused light spots on her skin, Michaela is now a professional ballerina who strives to make the art form more diverse
- **Jillian Mercado** (Today) – Fashion blogger Jillian Mercado beautifully modeled the clothes, her wheelchair and herself as part of Diesel's 2014 ad campaign "We Are Connected"
- **"Because Who is Perfect? Get Closer"** – Campaign by Swiss organization Pro Infirmis that showcased custom-made mannequins based on people with a variety of conditions
- **Tess Holliday** (Buzzfeed) – First model of her size and height to be signed to a major agency that started a Twitter hashtag to show the many representations of beauty
- **Jamie Brewer** (Time) – Actress known for "American Horror Story" and the first model with Down syndrome to walk the runway at NY Fashion Week