

My Flesh and Blood

A Study Guide

Prepared by Roberta McNair

for CFI Education

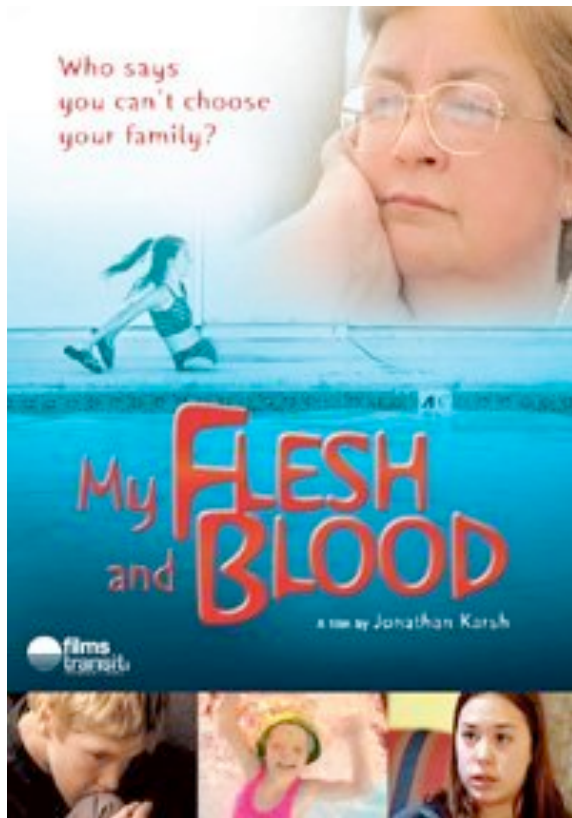
A Place in the World



Table of Contents

About the Film	3
<i>My Flesh and Blood</i>	3
<i>SXSW 2003 review</i>	4
<i>Blog Post</i>	4
About the Director.....	5
<i>SXSW 2003 interview with Jonathan Karsh</i>	6
About the Toms	9
<i>The Toms' story</i>	9
The “Special” Child	12
<i>Cloe—Arthrogryposis</i>	12
<i>Katie—Fetal Alcohol Syndrome (FAS)</i>	12
<i>Anthony—Epidermolysis Bullosa (EB)</i>	13
<i>Libby—Spina Bifida (SB)</i>	14
<i>Faith—Severe Burns</i>	14
<i>Joe—Cystic Fibrosis (CF)</i>	15
An Historical Perspective	17
Activities and Questions for Class Discussion	19
Resources	20
<i>Documentary films about disabilities</i>	20
<i>Dramatic films about disabilities</i>	20
<i>Books about families and disabilities</i>	21
<i>Online resources</i>	21

About the Film



My Flesh and Blood documents one year in the life of the Tom family of Fairfield, CA, which, at the time of the filming, consists of Susan Tom, a single mother, and her nine adopted “special needs” children. The filmmakers follow Susan and her children through their daily routines while they cope with the burdens and joys resulting from the children’s various conditions.

In particular, the film tracks the difficulties all of them face from one child’s—Joe—frustration, anger, and illusions, resulting from his physical and mental conditions and the limits on the curative power of love and acceptance without support from appropriate social services. Joe’s conditions and behavior are a catalyst in the lives of the eight other children in the Tom household—and mother Susan. In addition to the difficulties the children face at school and outside their home, they must

deal with the very real threat that Joe poses to their growth, happiness, and safety.

Interviews with members of the Tom family intersperse the unscripted activity, allowing the audience to gain an understanding into Susan Tom’s reasons for adopting so many children with special needs as well as the children’s candid thoughts and feelings about their mother, their family, their handicaps, and their challenges.

The Tom Family includes mother Susan; her “home-grown” sons Jeremy and Ben; and adopted children Emily, Margaret, Anthony, Cloe, Faith, Hannah, Joe, Katie, Libby, Susie, and Xenia.

My Flesh and Blood

Director Jonathan Karsh

Producer Jennifer Chaiken

Editor Eli Olson

Director of Photography Amanda Micheli

Awards:

Sundance Film Festival 2003: Audience Award, Documentary; Director’s Award, Documentary

International Documentary Association 2003: Honorable Mention, Features

Florida Film Festival 2003: Special Jury Award, Best Documentary Feature

Amsterdam International Documentary Film Festival 2003: Audience Award; FIPRESCI Prize

Meet the Toms, LLC, the production entity for *My Flesh and Blood*, received a \$5,000 grant from the Christopher Reeve Paralysis Foundation to complete the editing of the film.

http://www.imdb.com/name/nm1285615/?ref_=ttfc_fc_dr1 ,

www.myfleshandbloodthemovie.com,
www.christopherreeve.org/site/c.geIMPL0pGjF/b.1029295/k.64F6/Quality_of_Life_Grants.htm

SXSW 2003 review

By Roxanne Bogucka

[Jonathan] Karsh spent a year in the Tom household, where industrial-strength mom, Susan Tom, cares for her 13 children, most of whom are handicapped and most of whom she adopted. *My Flesh And Blood* was both amazing and uncomfortable to watch. This is a household filled with a great deal of stress. Some of Tom's kids have handicaps that barely trouble their daily lives. Two of her daughters are legless, cheerful, and well-adjusted. One daughter's face is disfigured from having been badly burned as an infant. But one son suffers from a form of cancer that causes painful wounds all over his body and will ultimately kill him, and another son has both cystic fibrosis and severe emotional disturbances. And Tom's biological daughter, the oldest of the brood, is about to melt down under the demands of home life, a supermarket job, and the transition to being a college student.

It feels really invasive to be a fly on the Toms' wall, partly because the subjects here are children, but also partly because Susan is an ambiguous presence. Susan's parents come for a visit and are clearly overwhelmed in no time flat. They speak of Susan's need to give as a trait they observed in her youth. It's clear that Susan is not only performing a heroic service, she loves caring for these kids. But as an outsider viewing the household, it also seems that Susan's need to be needed overrules her responsibility to provide the best childhood she can for her kids, especially her eldest, whose life has both suffered and been enriched by so very many, very needy siblings. Not quite the hymn of praise you thought it would be at first, *My*

Flesh And Blood is a compelling domestic train wreck.

<http://www.hybridmagazine.com/films/0403-sxsw/reviews/r-bogucka.shtml>



Xenia and Faith

Blog Post

By Kayce Naughton, December 23, 2011

Over the summer I watched a documentary called "My Flesh and Blood" about a family of multiple disabled children whose disabilities ranged from hyperactivity to actual physical problems. Susan Tom, a single mother, adopted all of the children on top of her three birth children and has created an amazing life for all of the children. Susan Tom lives off of social security and payments for each child and works hard to keep each child happy and safe. Her life gets hard at times, especially when one child is in the hospital or one is throwing a tantrum. Someone has to be a very special person in order to do the things that Susan has done for these children. I don't think I know anyone who would be able to do the things that Susan has done and still survive healthily. I don't even know anyone in the world who would try. Why can't such great people like Susan be more common? If everyone was as great as Susan I believe our world would be perfect. Why are people so scared to help and do great things?

<https://kaycenaughton.wordpress.com/2011/12/23/susan-tom-an-inspirational-woman/>

About the Director

My Flesh and Blood is Jonathan Karsh's first feature-length documentary. It grew out of his experience reporting and producing short news and special-interest stories for various television programs for 15 years.

Among the subjects Karsh covered during those years was the Sundance Film Festival, which gave him exposure to the best in current documentary films. As Karsh noted in a 2005 interview, "I would see documentaries and covered Sundance and was so moved by so many films, I just wanted to give an audience that same experience."

The hectic pace of daily television work started to wear on Karsh. While he was working as a host and writer on KPIX TV's Evening Magazine, he was assigned a story that would send him in a new direction. "My producers for this TV show I was doing in the Bay Area said, 'Oh, you're meeting this woman and her 11 kids. Go do it,'" Karsh related. "And it was just supposed to be another day at the office. I couldn't have cared less."

Karsh continued, "But when I met Susan and these kids, it really changed my life. I was so taken and shaken by the kids and Susan, I just wanted to follow up. I was sensationally curious about them and how they operate, how they function with these disabilities, and how Susan does it."

In contrast to the hurried nature of his previous work, taping a story in the morning, editing it in the afternoon, and airing it that evening, Karsh discovered the dedication that creating a documentary film requires. Karsh spent one year with the Tom family, the first weeks of which were on the road with them as they took a cross-country trip to visit landmarks and family. Karsh initially intended his film to be about that vacation, but he

realized the deeper story was in the Tom family's day-to-day lives.

It was a full-time job Karsh and his film crew. "It was around the clock," Karsh said, "talking, shooting, being with the Toms." They shot about 120 hours of footage, winnowing it and many hours of the Toms' home videos down to 84 minutes.



*Director Jonathan Karsh at
Sundance Film Festival*

Susan documented her family's important times, as Karsh related. "Susan shot so many holidays and firsts when the kids would come. She would go to Russia and pick up four new kids. She would come home and then she would shoot their first Christmas on her little home video camera. So there were many, many hours of footage to sift through. I used a lot of it in the movie."

Most of the film was shot with only one camera crew, composed of the Director of

Photography, Amanda Micheli on camera; Craig Burton on sound; and Karsh. Susan Tom insisted that the film crew participate in the life of the family before she would agree to the documentary. Everyone in the crew had to commit to staying in the children's lives, because, according to Susan Tom, they had already suffered so much loss, for the film crew come into and then leave their lives would be too painful. These factors result in a documentary feature that gives its audience an emotional experience a more objective style of filmmaking might have provided.

Karsh's working title for the film included *Meet the Toms*, among others. It was when Karsh was discussing Joe and his potential danger to the family with Susan Tom that he asked Susan why she didn't send Joe to a facility that could better manage his emotional problems. Although Joe, like most of his brothers and sisters, was Susan's adopted child, she responded that she would not do that, because he was her flesh and blood. Karsh saw the power in that phrase as the film's title, not only because of how Susan views her relationship to her children but also because so many of the children deal every day with issues of their own flesh and blood.

Asked if he had plans for a sequel to *My Flesh and Blood*, Karsh responded that he had no plans for one but that he would like to make a film that followed Faith Tom through her life. To that same question, Susan Tom emphatically responded, "No."

Karsh is a native of Sacramento, California—about 45 miles from the Tom family's home in Fairfield—the son of a psychiatrist and a social worker. Karsh started his career in television hosting Sacramento's locally produced TV magazine called *Scratch* before moving to San Francisco and KPIX, where he hosted *Evening Magazine* from 1998 to 2001. After making *My Flesh and Blood*, which was released in 2003, Karsh moved on to other

television projects, including directing the segments "Left of the Dial" for America Undercover for HBO and "Lookalikes" for The AMC Projects. In 2006, was supervising producer for the series *Back on Campus* on ABC-Family and co-executive producer for the episodes "After the Storm: Mississippi," "After the Storm: New Orleans," and "After the Storm: Texas" on *Extreme Makeover: Home Edition* on ABC.

Karsh was the host of *Kid Nation* in 2007, and since 2006 he has produced numerous "reality" programs for network and cable television.

<http://movies.about.com/cs/upcomingreleases/a/flbl31125033.htm>, http://www.imdb.com/name/nm1285615/?ref_=ttfc_fc_dr1

SXSW 2003 interview with Jonathan Karsh

Jonathan Karsh made a beautiful, draining documentary about Susan Tom and her family of 13 children, most of whom are disabled or ill children she has adopted. Senior editor Roxanne Bogucka got to speak to Karsh after the only screening of his film at South by Southwest.



Roxanne Bogucka: ... I'm with Jonathan Karsh, first-time director—?

Jonathan Karsh: Yes.

RB: —of the movie *My Flesh And Blood*. Welcome to Austin and South by Southwest.

JK: Thank you.

RB: How did you identify the Tom family? How did you find them?

JK: I found the Tom family when I was working for a television show in San Francisco. It was a quick, two-, three-minute story that we did about the Tom family, and I wanted to follow up and make a longer documentary. So I asked Susan, she said, "You've got one year to do it," Susan Tom, who is the subject of the film. And she said, "Get it done in a year and we'll see what happens." And that was the film.

RB: How did you... first, you'd been working in TV, but how did you get the gig of getting to make a movie? I understand your producer to say it was budgeted for under \$300,000. That's kind of a pressure-filled gig for a first-time filmmaker. How'd you get into that?

JK: Well, the producer of the movie is an old friend of mine, so we had a relationship before making the film that made it easy to jump into something together. And she put a lot of trust in me, and I wanted to do a good job because of her faith in me. So I put all my energy into making sure I pulled it off.



Tom family outing

RB: Now talking about trust, how did you gain the trust of the Tom family? There's 13 kids in this family, plus the mother. So I understand you went on a road trip with them. Could you talk a little about gaining the trust of the family?

JK: Yeah. The movie began with a road trip across the country. That's what I thought

would be the subject of the film. And while we were shooting I got to be kind of a very close friend of Susan Tom and an older brother to the kids. And it gave Susan an opportunity to get to know me as a person and to realize that I wasn't trying to make an exploitative film about this family. I was trying to make strong, human drama. And once she understood that, she put a whole lot of trust in me. And now we're great friends. Susan and I are buddies, and we talk all the time. We see each other all the time, and it made it easy because we had a really close friendship. And I don't know how people make films about people they don't know well. That must be a real challenge to do it. For me it wasn't a challenge. It was actually a pleasure to spend this much time with someone I really liked.

RB: With this sort of film you had to be a fly on the wall. How much time did you spend in the household each day, and over what time period?

JK: We shot over the course of one year. We shot inconsistently, day-to-day. We never went more than a week without shooting, but some days it was a 20-hour shoot and some days it was a 5-hour shoot. And some things we were shooting specifically because we knew something might happen, and some days we were just shooting to get coverage of the house, and then something did happen. So it wasn't ever routine. It was really an inconsistent year of shooting here and there, and some times more than others.

RB: How do you deal emotionally when you're making a film with something like... I think I just find it hard that, you can see the shit's going to hit the fan today. Things have been building to a head, and you really want to get it, you know? And then at the same time, there are these people whom you've come to care for now. How do you do your job with that sort of stress, I guess is what I'm asking?

JK: I think you stay as objective and as detached as you can. You try not to interfere. You try to just be there for what can potentially happen, and then you hope something interesting unfolds. And as long as you stay out of the way... you know, you figure out a documentary in the edit room. You don't really figure it out while you're shooting. So we just shot and shot and shot and shot and shot, making sure we were in the right place, but beyond that we weren't analyzing too much of how not to interfere and how not to shoot too much or too little but just get as much as you can and then figure it all out once you're back putting it together.

RB: So when you were editing, were there any stories or any moments that you wish you had been able to incorporate but that you had to leave behind?

JK: No actually. All the stuff that I wanted to put in the movie is in the movie. There wasn't anything left out that didn't make the film. Everything that is worth seeing is in the film. Other than other great things that the kids say. You know, their interviews were hours and hours long, and they had a lot of zingers. One of the girls without legs said, "I just don't want legs. I don't want a sprained ankle." And Faith, who's the burned girl, was full of funny, really precocious comments that we couldn't use in the movie. So a lot of interview, but outside of that, you're seeing all the good stuff. ...

RB: What sort of project would you like to work on next? Or are you already involved in something?

JK: I'm starting to work on another project and it's totally different than this. I think the next thing I want to do is, is... anything that's different than this. And try to make films that are so different from each other that it's difficult to distinguish a style, you know. I don't want to get pigeonholed into just doing

family movies or just doing disability films. To try to do a whole myriad of films, so actually whatever's next is going to be anything not like this movie. Only for my own, just my own sanity.

RB: Fair enough. Thank you very much.

JK: You're welcome.

<http://www.hybridmagazine.com/films/0403-sxsw/interviews/karsh.shtml>

About the Toms



Top row, left to right: Katie, Emily, Margaret, Ben, and Joe Tom. Second row: Hannah, Faith, Xenia, Susie, Jeremy, and Anthony Tom. Front row: Libby and Cloe Tom.

The Toms' story

Eleven years ago, Susan Tom was bringing her adopted daughters Hannah and Xenia (then 2 1/2 and 5, respectively) into the country from Russia.

As they were checking through security, the guard dutifully searching their strollers suddenly recoiled in horror.

"Oh, my God!" he shouted. "They don't have any legs!"

"Oh rats," Tom replied in as close to a bored monotone as she could muster. "I must have left them on the plane again."

—C.W. Nevius, *San Francisco Chronicle*, November 25, 2003

<http://www.sfgate.com/bayarea/nevius/article/One-adoption-led-to-another-now-Susan-Tom-s-2547991.php>

Anyone who has seen *My Flesh and Blood* has seen a family that deals with the ups and downs, joys and heartaches, and victories and adversities of life uncommonly. Buoyed

and encouraged by their mother's indefatigable sense of humor and optimism, the Tom children face difficulties most people cannot imagine, let alone live with every day. But this very special family didn't come together through any grand design.

Susan Tom and her ex-husband had two children together, sons Jeremy and Ben. Susan wanted a daughter, as well, so the couple adopted Emily and later Margaret. Emily developed arthritis while she was a baby and Margaret was a premature baby born with brain damage that required early brain surgery and a permanent shunt. The marriage didn't survive long after these adoptions.

As a single mother, Susan adopted nine other children, all of whom had special needs. Susan only differentiates between her first two sons and her 11 adopted children by referring to the first two as "home grown." The film makes clear that the children's disabilities are only part of who they are; Susan has instilled confidence and individualism in each child.

In the film, Ben and Jeremy are out of the house but still are involved with activities. Emily goes to school and works, living on her own but maintaining close ties with the family. Margaret is starting college and looking forward to life on her own, but she acknowledges that in spite of all of her household responsibilities, it's probably harder to live alone than in her family.

Xenia and Hannah were born without legs, yet they demonstrate fierce physical strength and independence. Libby was born with spina bifida, confining her to a wheelchair for mobility, but it never slows her down. Cloe was born with arthrogryposis, a condition in which the joints of her limbs cannot bend, but nothing stops her from running and playing.

Katie was born with Fetal Alcohol Syndrome, leaving her with developmental disabilities, yet she interacts with her siblings on a sure footing. Faith suffered burns over her head and upper torso when she was an infant, requiring numerous surgical reconstructions and skin grafts to help her look normal, but she looks forward to earlobe reconstruction so she can wear an earring. Joe has cystic fibrosis, a fatal disease that impedes breathing because of a sticky, thick mucus, as well as bipolar disorder, attention deficit disorder, and diabetes, but he can be as loving as he is confrontational.

Anthony was born with epidermolysis bullosa (EB), a painful skin disease in which a defect in a collagen gene causes the skin to infect and fall off of the body with the mildest bump or abrasion, yet his deadpan humor and inner calm keep his brothers and sisters on an even keel. Another daughter, Susie, also suffered from EB and died of her disease two years before the making of *My Flesh and Blood*.

When *My Flesh and Blood* was made, the Tom family lived in Fairfield, California, in a two-story home that had been expanded and adapted to a large family with physical restrictions. The film shows the Toms going through its days and nights as a family full of different personalities and different needs.

My Flesh and Blood is no Hallmark card to the Toms. Family members are shown at their best and their worst, from the first scene. After Joe tells the camera that he hates his sisters and brother and that he's glad he doesn't have any of their disabilities, he then threatens that if he can figure things out he's going to kill one of them. Susan noted in an interview, "It's surprising how many people laugh at the beginning. They don't know how to take it. No, he meant it. If you watch his eyes you can see him descend into madness. He was slipping and he couldn't figure out how to hold on."

Xenia is confident enough to ask a boy to the school dance, but when he doesn't show up, it's there on film. Anthony shines performing in his school's skits, yet his pain is clear when Susan bathes him in a bleach-and-water solution and rewraps his raw skin, a procedure that Susan tells the audience must take place four times a week to reduce infection.



Susan Tom in 2013

Faith is bright and bouncy as she goes through her days, but the audience learns that school is very hard for her, because the children tease her about her burn scars. Even home is not a perfect sanctuary, because she is driven to tears and the privacy of her bed when Joe's cruelty becomes unbearable. And Margaret, shown so happily anticipating college and discharging her responsibilities suffers a meltdown on camera and begs her mother to talk to her, only to be put off until morning.

Susan's days never seem to end, and she expresses her own frustrations frankly, presenting her outlet for her needs—fantasy online dating and meals out alone. These demonstrations of fallibility never detract from what each of the Tom children knows and many express: that Susan loves every one of them because of and spite of everything about them.

As Jonathan Karsh expressed it, Susan sees all of her children as her flesh and

blood. The film shows each member of the Tom family as a complete flesh-and-blood person. It just happens that for many of the Tom children, the condition of their flesh and blood can affect how the world looks at them and even if they will live or die.

www.johnlainghomes.com/Get/InTheNewsItem.asp?PressReleaseID=227 , <http://abc.go.com/primetime/extremehome/bios/304.html>

After the shock of Joe's death, Anthony celebrates his 20th birthday at the end of *My Flesh and Blood*. However, his disease took its complete toll three days before Christmas 2004, when Anthony died at the age of 22.



ABC / David Moir

Extreme Makeover: Home Edition shows the Toms their new house

My Flesh and Blood is not the only recognition the Tom family has received. After a member of the crew saw the film on HBO, in November 2005, *Extreme Makeover: Home Edition* chose Susan and her family to receive "a home that doesn't discriminate against them." The family now lives in a seven-bedroom, six-and-a-half bath, three-story home that includes an elevator, voice-activated lighting, and wheelchair-level counters in the kitchen.

In addition, the home's builder, John Laing Homes, donated \$300,000 to the Tom Family Education Fund, and Countrywide Mortgage paid off the mortgage on the Tom's original house.

The “Special” Child



Susan Tom listed the disabilities and conditions of each of her children during an interview on CNN in 2003, soon after the release of *My Flesh and Blood*:

“Anthony is 21. He has the genetic skin disease which causes a glitch in your collagen seven, which is what keeps your skin stuck to you. Margaret is 20 and she was premature and had brain surgery. Emily is 17. Xenia is 16 and she was born without legs. Katie is 15 and she has fetal alcohol syndrome and mild cerebral palsy. Hannah is 13 and she was born without legs. Cloe is 10 and she has arthrogryposis, and you’re born with joints that don’t bend. Libby is 11 and she has spina bifida. Faith is 10 and she was badly burned when she was four months old. And Joe is 15 and he has cystic fibrosis and diabetes and is bipolar.”

<http://transcripts.cnn.com/TRANSCRIPTS/0312/25/ltm.19.html>

To have a more complete understanding of the Tom family, it helps to understand the diseases and handicaps the children were born with, developed, or received.

Cloe—Arthrogryposis

In Greek, arthrogryposis literally means “curved or hooked joints.” The term describe multiple joint contractures, or permanent shortening, present at birth. The contractures

result a deformity or distortion of joints. The commonest form of arthrogryposis, present in 40% of cases, is a condition called amyoplasia, which means a deficiency in development.

The cause of arthrogryposis is not entirely understood and it may vary from case to case. In many cases nerve, muscle, and connective tissue have not developed normally. Lack of movement during fetal development is also a cause. The condition can be a genetic defect, but environmental factors, such as drugs absorbed by the fetus, can also be a cause. One in 3,000 children is born with arthrogryposis.

Cloe’s treatment is not discussed in *My Flesh and Blood*, but the options for a child with arthrogryposis are daunting and limited. Any treatment requires coordination among a multi-disciplinary team, including the pediatrician, neurologist, orthopedic surgeon, geneticist, physical therapist, and occupational therapist. The aim of any treatment is to improve function, not to make the child look “normal.” Before any kind of surgery to correct Cloe’s condition could be considered, she would have to undergo therapy and bracing of her joints.

Cloe has normal intelligence and aptitude, but she will never move like other children. The film demonstrates, however, that this condition does not stop Cloe or even slow her down. And since this condition has no effect on her general health, Cloe can expect to live as long as anyone else.

www.orthoseek.com/articles/arthrogryposis.html

Katie—Fetal Alcohol Syndrome (FAS)

Fetal Alcohol Syndrome (FAS) is a disorder characterized by mental and physical birth defects as a result of a woman drinking alcohol when she is pregnant. It is estimated

that FAS is the leading known cause of mental retardation, occurring in one out of every 750 live births. An estimated that 5,000 infants are born each year with FAS.

The effects of a woman drinking alcohol when she is pregnant differ throughout the stages of the pregnancy. Early exposure presents the greatest risk for serious physical defects. In the first trimester, alcohol can affect the way the cells are growing, altering tissue growth in the fetus. The alcohol also diminishes the number of cells growing in the brain, causing the brain to be smaller. While miscarriage is the greatest risk in the second trimester, in the third trimester, the fetus has increased chances of neurological and growth deficiencies when exposed to alcohol.

There is no cure for FAS, however, surgery can repair some of the physical problems, and a special school program can assist with mental and physical development. Early recognition of FAS is crucial to the child. Research shows that attention to mental and physical stimulation and development before the age of five make a tremendous difference in how well a child will function with FAS.

Katie has the benefit of being in a loving and stimulating environment in the Tom household. Susan and Katie's brothers and sisters provide her with attention and affection, which go a long way in helping a child with FAS.

Adults with FAS often have difficulty maintaining successful independence. They have difficulty staying in school, staying employed, and sustaining personal relationships. Without the proper treatment and supervision, individuals with FAS are at risk of developing mental illnesses, getting into trouble with the law, abusing alcohol or other drugs, and having unwanted pregnancies. However, the foundation that Katie is receiving in her large, busy household may prepare her to overcome many of the

difficulties other children with FAS face as they grow up.

www.specialchild.com/index.html

Anthony—Epidermolysis Bullosa (EB)

Epidermolysis bullosa EB is a group of diseases characterized by blister formation after minor trauma to the skin. This family of disorders, most of which are inherited, range in severity from mild to the severely disabling and life-threatening diseases of the skin. This rare genetic disorder affects all ethnic and racial groups. Estimates indicate that as many as 100,000 Americans suffer from some form of EB.



Susan Tom performing Anthony's bathing and bandaging regime

Think about what Anthony suffered from the time that he was born: Imagine a child with painful wounds similar to burns covering most of his or her body. Unlike burns, these wounds never go away. Anthony could never ride a bike, skate, or participate in sports because the normal play of children causes chronic sores. Wounds likely covered up to 75 percent of his body. Anthony could eat a diet of only liquids or soft foods, because blistering and scarring occur in the mouth and esophagus with EB. Scarring caused the fingers and toes to fuse, leaving deformities that severely limited his function. Anthony led a life in and out of hospitals for wound treatment, blood transfusions, biopsies, and surgeries. His eyes often blistered, preventing

vision for days at a time. He suffered from chronic anemia, which reduced his energy and retarded his growth. There is little hope for life beyond 30 years for people afflicted with EB. Anthony died at 22.

www.ebinfo.org, www.ebkid.org

Libby—Spina Bifida (SB)

Spina bifida (SB) is a neural tube defect that is the most frequently occurring, permanently disabling birth abnormality. SB occurs from the failure of the fetus' spine to close properly during the first month of pregnancy. Infants with SB often have an open lesion on their spine where significant permanent nerve and spinal cord damage has occurred. SB can range from a mild defect that causes no problems at all to a more serious defect, which causes paralysis and loss of bowel/bladder control.

Myelomeningocele is the most severe type of SB. Although *My Flesh and Blood* does not give detailed information about Libby's disability, it is likely that she is afflicted with this most severe type of SB. In this form, not only does the protective covering of the spinal cord get pushed out through an opening of the spinal column, but the spinal cord itself also protrudes, forming a sac or cyst. Spinal fluid may leak out and result in a serious infection. This type of SB usually results in paralysis of the lower limbs and problems with bladder/bowel control, although the actual effect depends on many things including the size and location of the lesion, and the degree of damage to the spinal cord and nerves.

Libby must use a wheelchair, even in her home, which greatly restricts her activities. However, scenes in the film show her swimming with her sisters, which is a physically liberating activity for all of them.

Learning disabilities occur in approximately 80% of all children with spina

bifida and are more likely to occur in children with hydrocephalus. Children with learning disabilities tend to have poor eye-hand coordination, attention deficits, hyperactivity, and problems with memory, sequencing, organizing, problem solving, and decision-making. As with Katie, the loving and busy environment in which she lives provides valuable stimulation and models to imitate. The outlook for Libby is good, because with the latest medical advances, children born with SB will live into adulthood and can become independent, productive adults. Many adults with spina bifida are college-educated professionals working in a variety of fields.

www.sbaa.org , www.specialchild.com/index.html

Faith—Severe Burns

Susan Tom does not know the actual circumstances of how Faith came to be severely burned while she lay in her crib while she was an infant; she only knows the results. Because of the fire that started near her crib and caused the canopy over her to ignite and fall on top of her, Faith is scarred on her face, head, neck, torso, arm, and hand. She has no hair on her head. The damage to her hand caused her to lose fingers. Faith came to Susan with another name, but Susan believes everyone has to have faith, so she gave the child a new name.



*Faith's burns caused scarring
and the loss of her hair*

Faith suffered thermal burns, which are burns due to external heat sources that raise the temperature of the skin and tissues and cause tissue cell death or charring. Hot metals, scalding liquids, steam, and flames, when coming in contact with the skin, can cause thermal burns. An open flame is the leading cause of burn injury for adults, while scalding is the leading cause of burn injury for children. Both infants and the elderly are at the greatest risk for burn injury.

The film does not tell the audience how much feeling Faith has where she has been burned, but it is likely that the tissue death that occurred with the burning also caused nerve damage or death. Faith hopes to undergo more surgery as she gets older. She states that when she is finished having her surgeries she will look like everyone else.

There are 1.25 million burn injuries each year in the United States. In California alone, each year 10,000 people are burned severely enough to require medical attention; 4,500 are children. Prevention is the best way to avoid burn injuries and deaths. Faith will never know if the burns she received could have been prevented. What Faith does know is that, in a society that highly values physical appearance, it is important for every burn survivor to receive help to relieve their emotional suffering, create opportunities for socializing, and help build the skills necessary to cope.

www.aarbf.org

Joe—Cystic Fibrosis (CF)

Cystic fibrosis (CF) is the most common, fatal hereditary disease in the U.S. CF is a disorder of the cells that line the lungs, small intestines, sweat glands, and pancreas. Sticky, thick mucus contributes to the destruction of lung tissue and impedes gas exchange in the lungs. It also prevents nutrient absorption in the small intestines, and blocks ducts from the pancreas that

release digestive enzymes. Approximately 85% of all people with CF cannot properly digest their food without supplemental enzymes.

People with CF must follow a strict regimen for the treatment of this disease. This regimen includes taking medications such as antibiotics to fight respiratory infections, enzymes to aid in food digestion, and vitamins to improve general health. Some people with CF use aerosols to open restricted airways. To dislodge mucus from the lungs, people with CF must undergo chest physical therapy or other therapy methods; in some cases, they must use oxygen. People with CF also must follow a strict diet, and avoid people with colds or infections.

My Flesh and Blood shows Joe in the hospital two times, because of severe attacks from his disease. Joe is also shown performing his treatments at home. The audience sees and hears about the medications he must take, and references are made to the kinds of food he can eat and what he must avoid.

For any child, living within this restrictive type of regimen would be difficult; for Joe, the difficulties are increased because of his other problems. Joe, the audience learns, also is bipolar, has diabetes, and has attention-deficit disorder (ADD). Each of these conditions requires medication and specific lifestyle adaptation. In addition, the hardship and loss that Joe underwent when he was a child, including being moved from one foster home to another, have made him volatile and untrusting.

In many ways, the Tom household has been the best possible world for Joe. He is part of a family in which everyone has a special need, and so he doesn't stand out as "different." He fiercely loves his mother, Susan, and she loves him deeply and

devotedly. She assures that Joe always receives the medical care he needs and that he follows the rules to manage his CF and other conditions.

One crucial component for Joe's well-being is missing, however, and the audience sees Susan's frustration in not being able to provide it for Joe: Joe cannot receive the mental health care and treatment he needs, because the California MediCal system does not provide this care for terminally ill children. It is impossible to know if Joe's life would have been prolonged and if his years would have been happier and less troubled if he had been able to receive counseling and therapy along with the medications and treatments for his physical conditions.



*Tom family at dinner (Chronicle
photo by Michael Macor)*

Anywhere from 20,000 to 30,000 American children and adults have CF. One in 2,500 American children is born with CF. Approximately 1,300 new cases are diagnosed each year. Improved diagnostic techniques have resulted in newly identified cases in people of all ages. Twelve million Americans, or one in 23, carry the CF gene without symptoms. At present, only half of those who develop CF survive to age 30.

<http://www.cff.org/> , <http://www.cfri.org/home.shtml>

An Historical Perspective



Hannah Tom

Prior to legislation enacted in 1975, there was no U.S. federal requirement that free, public education be available to handicapped children. The previous decade saw changes in the attitudes toward caring for, educating, and integrating handicapped children into the mainstream of society, with laws in 1965 and 1966 that improved educational quality in primary and secondary schools and established federal grants for the education of the handicapped in public schools.

It may be unimaginable to Americans born after 1965, but up until recent years, handicapped children were generally kept from the rest of society, if they managed to live much past their births. Children with handicaps and disabilities—what we refer to as special needs children—were viewed by most people as unable to contribute to society and, therefore, a burden to it. Those who were born healthy and whole believed that a disabled person was less valuable as a person, and this was demonstrated in the language used to describe these children: defective, deformed, feeble minded, and unfit.

In the past, children with handicaps could suffer a range of fates. In ancient Greece, a “deformed” baby would likely be taken to a desolate location and left there to die. Ancient Rome left less to chance with its

early legal code, the Twelve Tables, which required deformed children to be killed. Although the term that rationalized this attitude and custom would not be coined until 1883, the word that describes these practices is “eugenics,” which literally means “good birth.” The act of killing a newborn child is called “infanticide,” and this practice has occurred throughout history, and still may occur today.

Recent centuries may not have experienced legislated infanticide, but the practice continued nevertheless, most often by the birth mother or a midwife, who assisted at the birth. A child born with a physical handicap and lived to adulthood would likely face a life of hardship and social ostracism. Two factors contributed to this: Conventional beliefs held that the handicapped could not contribute to society as well as the able bodied and that the handicapped were less intelligent than children that were born “whole.”

Such beliefs developed out of superstitions and misconceptions about the handicapped, and they were often based in fear as well as prejudice. Illnesses, mental conditions, and even moral weaknesses were believed to be inherited traits. People who were handicapped or “different” were an uncomfortable reminder of human frailty, and by the 19th century, many societies had established institutions to house the handicapped and ill, thus separating them from the general populace for its good and their welfare. Those who did not land in an institution often ended up homeless, begging for food and shelter, especially those who suffered a physical deformity, either from birth or injury.

These institutions housed the insane, the feeble minded (or “idiots”), epileptics, and other “deficients.” As medical science

advanced, it became the practice to sterilize the institutionalized so that their hereditary traits—believed to include alcoholism, criminality, insanity, idiocy, imbecility, and epilepsy—could not be passed on to taint society. More than half of the states in this country had “eugenics sterilization” laws by the middle of the 1930s, and doctors and institutions sterilized more than 20,000 people as mandated by those laws.

The pervasive attitude until recently was that there were two kinds of people, standard and substandard. Those who were substandard were believed to be less than human, which effectively denied them the rights and opportunities afforded to “standard” people.

Something that influenced a change in society’s attitudes towards the handicapped was a systematic program of eugenics practiced by the Nazis in Germany in the 1930s and 1940s. Institution and sterilization were only the first steps toward creating a society that was not only healthy but was also racially and morally pure. It was only a few short steps that took Nazi policy from protecting society from deformity and defective traits to exterminating any people who did not conform to the Nazi Aryan ideal, including the mentally retarded, Gypsies, homosexuals, and Jews.

Much of the world recoiled at learning of the Nazis’ practices, judging them to be repugnant, immoral, and indefensible. Many Americans began to reassess this country’s own forays into eugenics. Medical science’s advances provided objective information into the true causes of diseases, conditions, and handicaps that had preciously been shrouded in superstition and fear. Most educated societies now understand heredity,

eradicating the beliefs that mental retardation and criminality, among other conditions, are not genetic traits. They understand there is no correlation between physical handicaps and intelligence or ability.



Margaret, born prematurely and requiring brain surgery as an infant

With this knowledge has come a change in the attitude toward the place of the handicapped in society. Children with handicaps are no longer placed in institutions as a matter of course. It is now the norm for most handicapped children to remain with their families and receive education and assistance to help them become independent adults, living and working in the mainstream.

Laws affect attitudes, but attitudes enact laws. Laws that protect the rights of the handicapped regarding education, health care, and access to the world contribute to attitudes and greater acceptance of the differences in people. As attitudes change from fear and ignorance to matter-of-fact acknowledgement of differing physical and mental abilities and limitations—without judgment—the laws that protect the handicapped may become obsolete.

<http://eric.ed.gov/?id=ED140554> , <http://www.thefreelibrary.com/Eugenics%2c+euthanasia%2c+and+physician+assisted+suicide%3a+an+overview+for...-a0144013049>

Activities and Questions for Class Discussion

1. Go online and find out about SSI and MediCal. When were these programs started? Why were they established? Who qualifies to receive SSI and MediCal benefits? If you're online, download the application form for MediCal: http://www.dhcs.ca.gov/services/medi-cal/eligibility/Documents/2014_CoveredCA_Applications/ENG-CASingleStreamApp.pdf. See if you are able to complete the application. What, if anything, would you change in the application and the application process?
2. Research the foster care system in California. How does foster care differ from adoption? How does a child end up needing foster care? Who qualifies to be a foster parent? Are there different criteria for foster parents of special needs children? What, if anything, would you change in the requirements for foster parents?
3. Do research on burns and reconstructive surgery. How are skin grafts performed? How successful are skin grafts? Is it realistic for Faith to believe that she will look "normal" after her surgeries?
4. Had you heard of epidermolysis bullosa (EB), arthrogryposis, fetal alcohol syndrome (FAS), spina bifida (SB), and cystic fibrosis (CF) before seeing this film? How did you learn about them, and when you did, was it only as information or did you see or hear of people who have these disabilities?
5. Does it make a difference to understanding a disability to meet someone who has that disability? Conversely, does it make a difference to meeting or knowing someone with a disability to understand that disability? How and why?
6. In addition to the matter-of-fact presentation of Anthony's bleach-solution bath and bandaging, the filmmakers show home-video footage of Susie Tom's care and treatment. The audience learns that Susie died of the same disease that Anthony has. What impact does juxtaposing Susie and Anthony's care have on you? Do you know anyone who cares for a family member that requires home care, and what kind of care is it?
7. Research the field of eugenics. What were the goals of its progenitors, and how did those goals change as eugenics was adopted by ideologically driven groups?



Resources

Documentary films about disabilities

Gaias Børn, 1998, directed by Bente Milton

This documentary accompanies disabled British actor Nabil Shaban on a journey through history, from antiquity through Nazi Germany, examining the fate of those born disfigured and their impact on their societies. Difficult questions posed include the ramifications of advances in genetic science and what truly embodies beauty and perfection.

A Brief History of Time, 1992, directed by Errol Morris

Documentary about physicist Stephen Hawking, whose amyotrophic lateral sclerosis (ALS) limits his physical movement to two fingers and requires him to communicate through a voice synthesizer. Few people in the world—handicapped or not—are graced with the intellect and talents Hawking demonstrates.

Dramatic films about disabilities

My Left Foot, 1989, directed by Jim Sheridan

Christy is quadriplegic with cerebral palsy born into to a large, poor Irish family. His mother recognizes the intelligence and humanity in the boy everyone else regards as a vegetable. Based on the autobiography of Christy Brown, a wry and cantankerous writer who used his only functional limb, his left foot, to write.

Mask, 1985, directed by Peter Bogdanovich

Rocky is a seriously deformed but extremely intelligent and compassionate teenager who, with the love and support of his iconoclastic mother, is determined that he will

receive the same chances that everyone else takes for granted. He suffers from craniodiaphyseal dysplasia, which usually results in death during childhood. Unsentimental writing and performances enhance this story, based on the short life of Roy "Rocky" Dennis.

Books about families and disabilities

Parents Wanted, by George Harrar

Twelve-year-old Andy is a foster child who desperately needs and wants a loving home, yet he struggles with his past and the emotions evoked by his new life with his adoptive parents. The reader is drawn into Andy's world, where adults are not always reliable and a kid has to work hard to survive.

Adopting the Hurt Child: Hope for Families With Special-Needs Kids: A Guide for Parents and Professionals, by Gregory C. Keck, Regina M. Kupecky

Integrating social, psychological, and sociopolitical issues, *Adopting the Hurt Child* explains how trauma and interruptions affect children who have endured emotional and physical atrocities, failed reunifications, and myriad losses associated with multiple moves in the foster-care system. Their experiences impede normal development often severely undermine their capacity to function in a loving family and in society.

Living in my Skin, by Lori Hickman

Parents of children with a variety of disabilities speak about their lives with searing honesty. In this lengthy series of email responses to Hickman's questions, parents share the isolation and struggles they face each day in meeting their children's basic needs. They share their experiences on a variety of poignant issues, including finding out about their children's disabilities, difficulties in finding services and support, and heartfelt concerns for the future. Most of the children in her book have severe disabilities, such as autism, Down syndrome, CHARGE syndrome, quadriplegia cerebral palsy, Rett syndrome, and fetal alcohol syndrome. The children range in from age two to teenage.

What It's like to Be Me, by Helen Exley

Children from all over the world tell their stories about their lives and their disabilities. They tell how they see themselves and how they want to be seen by others. The book includes illustrations by the children who tell the stories. This is a wonderful book for parents to read to their young children.

Online resources

Information about the handicaps, diseases, needs of, and resources for special needs children, www.specialchild.com/index.html and <http://specialed.about.com/od/physicaldisabilities/a/physical.htm>

Oakland Children's Hospital Cystic Fibrosis Program, <http://www.childrenshospitaloakland.org/main/departments-services/cystic-fibrosis-program-80.aspx>

Information on cystic fibrosis (CF), <http://www.cff.org/> and <http://www.cfri.org/home.shtml>

Information on spina bifida (SB), Spina Bifida Association, www.sbaa.org

Information on epidermolysis bullosa (EB): EB Info World, www.ebinfofworld.com

Information about arthrogryposis, www.orthoseek.com/articles/arthrogryposis.html

Articles and resources for parenting children with disabilities and special needs, www.comeunity.com/disability/

Resources for special needs children and adoption information, www.adopting.com/special.html

Text of Public Law 94-142, <http://eric.ed.gov/?id=ED140554>

Center for Parent Information and Resources, <http://www.parentcenterhub.org/>

National Adoption Center, www.adopt.org

Alisa Ann Ruch Burn Foundation, www.aarbf.org

Burn Prevention Foundation, www.burnprevention.org

