

RAISING AWARENESS OF INVISIBLE ILLNESSES USING DOCUMENTARY MEDIA

A CREATIVE PROJECT

SUBMITTED TO THE GRADUATE SCHOOL

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE

MASTER OF ARTS

BY

SARAH LU ENGLAND

CHAIRPERSON

MS. SUZY SMITH

BALL STATE UNIVERSITY

MUNCIE, INDIANA

DECEMBER 2013

TABLE OF CONTENTS

TITLE PAGE	
TABLE OF CONTENTS	1
ACKNOWLEDGMENTS	2
INTRODUCTION	3
LITERATURE REVIEW	5
Documentary's Evolution	5
Documentaries for Social Change and Public Health	8
Documentary filmmaking's process	12
Purpose of Creative Project	15
METHODOLOGY	16
Pre-production	16
Interview Material	19
Production	20
Post-production	22
RESULTS	23
BODY OF PROJECT	24
SUMMARY AND IMPLICATIONS	25
REFERENCES	27
APPENDICES	29
Appendix A – Video Transcript	29
Appendix B – Mrs. Kathy Bruner Project Critique	39
Appendix C – Mr. Terry Heifetz Project Critique	43

ACKNOWLEDGMENTS

The person I have to thank first is Suzy Smith, who I feel is like the other half of this project. Thank you for giving me guidance while letting me discover my own way, supporting me by being tough on my work, and talking to me about life. Thanks to my evaluators. To Kathy Bruner, who has always made me want to do my best in everything I do and never settle in life. To Terry Heifetz, for brightening people's days with his smile and words, as well as his support and conversations during the early stages of Rachel's Story.

Part of me wishes I didn't have to make this project, because that means my sister Rachel wouldn't be living with illnesses. Yet I see all the strength, growth, and just pure gumption she throws in the face of these illnesses, inspiring many people of all ages. We like to remind her that she is not perfect, as all siblings do, but she is pretty fantastic and makes me want to live life better; and so does everyone else in my family. To my guardian parents, Peter and Bekah Hale, for showing me how to be a communicating and loving human being. I can never thank you enough for loving me like you do. To my siblings: Jonathan, Abbie, David, Maggie, and Ruthie.

Every part of who I am is in this project, and that includes my birth mom and dad, Alice, and Yvonne. Cancer enjoys being invisible at times, as it was in the beginning of my mom's war with cancer, which led to her passing years ago. This is also for her, my dad, and my sisters.

As for my new family in my life, thank you Fred and Kathy England for the support while I tackle this paper and project, as well as celebrating and loving me as your own daughter.

Lastly, I wouldn't be able to make it this far and be joyous if it weren't for my constant love, humor, and encouragement that is my husband, Ben. His support began long before I began this project and degree, and it stays with me as I continue finding my true passions.

I lied. My last thanks are to the grace of God that carries me through each day.

INTRODUCTION

For many years, documentaries have been used to expose truth, enlighten viewers about social issues, and provide a window into worlds that the viewers would never be able to experience otherwise. Public health and advocacy for people with serious illnesses, like HIV/AIDS, have become a relatable and widespread category. More recent and famous documentaries, such as Michael Moore's *Fahrenheit 9/11* (2004) and *Super Size Me* (2004), directed by and starring Morgan Spurlock, have paved the way for widely acclaimed and widely viewed feature documentaries (Higgins, 2005). Before these documentaries, however, television programs like PBS' *Frontline* were serving audiences, and they have continued to do so since 1983 (Frontline, 2013). PBS' *P.O.V.* is in its 25th year of airing "documentaries with a point of view" (P.O.V., 2013). PBS' programs like the ones mentioned have remained consistent and reliable as a source for important and impactful documentaries, which have included those focused on medical issues or illnesses.

Specific illnesses, like Alzheimer's, brain tumors, and cancer, have found a voice within research and documentaries. For example, HBO Documentary Films presented a project involving four 15-minute documentaries about Alzheimer's in 2009. PBS aired a documentary and campaign titled *The Truth About Cancer* in 2008. Cancer, which could be seen as one of the most pervasive illnesses in the world, will also be the subject of a six-hour documentary to be created by filmmaker Ken Burns and author Siddhartha Mukherjee (Bauder, 2013). The documentary, in partnership with advocacy group Stand Up to Cancer, will be based on Mukherjee's Pulitzer Prize-winning book, *The Emperor of All Maladies: A Biography of Cancer*, and is scheduled to air on PBS in spring 2015.

However, these common illnesses are not the only types that afflict people on an everyday basis. Some people are sick with an illness or disability that can be seen, such as chicken pox, yet other people battle with illness that cannot be physically seen, like diabetes or cystic fibrosis. The latter type of illness is called an “invisible illness” (Moran et al., 2005). Many invisible illnesses are chronic, meaning persistent and long-term. In the media, the topic of invisible illnesses and certain lesser-known illnesses are seldom the central subject matter taken on by well-known documentary filmmakers. While many types of illnesses have been featured in documentaries, these illnesses are almost always the most common ones people would think of first, such as cancer or Alzheimer’s. Invisible illnesses remain relatively untouched in the documentary world. It is for this reason that this project is proposed.

The conceptual idea is to produce a 60-minute documentary, comprised of several segments focused on a handful of individuals and their struggle with invisible illness, as well as perspectives from their families, friends, and medical support. Each individual will be the subject of one segment. For the purposes of this project, only one segment will be produced. It will be 10-15 minutes focused on one individual named Rachel and her struggle with invisible illness. It needs to be noted that Rachel is this author/producer’s sister.

Rachel suffers from three rare and chronic invisible illnesses. The first illness is called Autonomic Instability, a form of what is known as Dysautonomia, which deals with the automatic nervous system (ANS) in the body (“NINDS”, 2011). Normally, people’s bodies automatically regulate heart rate and blood pressure when they stand up or walk around. Rachel’s body, however, is incapable of doing this. It is important to differentiate Dysautonomia from regular high blood pressure, or hypertension, which is often caused by things like family history, increased age, and living unhealthy lifestyles (“Understanding,” 2013). Moreover, while

hypertension results in raised blood pressure, Rachel's blood pressure drops. Before being prescribed helpful medicines that stabilize these symptoms, Rachel's blood pressure has hit dangerously low levels. Dysautonomia strictly deals with the ANS and can impact a person's ability to physically move around. It can also become a primary condition of other diseases, like Parkinson's disease. Rachel also suffers from Dysmotility syndrome. Dysmotility syndrome, "affects a person's ability to digest certain foods" which then requires intravenous nutrition (Drumm, 2012). The third illness Rachel battles is an extremely rare illness known as SMAS, which stands for Superior Mesenteric Artery Syndrome. This is a rare condition that involves compression of a portion of the small intestine that runs between the aorta, the biggest artery in the body, and the superior mesenteric artery (Matheos et al., 2009). The produced segment will follow Rachel's story of her struggles with these conditions, which are uncommon, lifelong and invisible to most people. At the same time, the segment will showcase how Rachel maintains the relatively normal and average life of a young adult, especially considering the invisibility of her conditions.

This paper discusses research that supports a documentary focused on both public health and social issues and the methodology that will be used to produce the segment about Rachel. Limitations and elements of the project's progression are shared as well.

LITERATURE REVIEW

Documentary's Evolution

Many film histories note the origins of the documentary genre to the Lumière brothers and their first short films. These films showed everyday type of scenes, including workers coming out of a factory, a train arriving in the station, a baby's lunchtime, and a game of cards in

the garden (Higgins, 2005, p. 23). Since this time, there have been many cinematic technical advances and documentary styles to add to the genre.

The documentary genre can be classified differently from fictional genres through certain characteristics. Classically, documentaries have hand-held cameras, lower budgets and production values, and feature real life people ‘playing themselves’ instead of actors ‘playing roles’ (p. 23). Most of this is true, although documentary styles have changed in the way of camera angles and style choice, as well as higher production values due to advances in equipment and technology. But some audiences still have a hard time defining documentarians. Author Erik Barnouw stated that documentary filmmakers could be classified into the following categories, “explorer, reporter, painter, advocate, bugler, prosecutor, poet, chronicler, promoter, observer, catalyst, and guerilla” (p. 23). Moreover, with the increasing media options and availability, there are even more opportunities for individuals or groups to become documentarians and produce movies about their passions.

Although documentaries have arguably been in existence since the beginning of cinema, scholars have discussed and written on how and why the documentary genre has skyrocketed in the recent years (Higgins, 2005, p. 23). What has happened is an increase in the public’s appetite for documentaries, especially in the last decade with the financial and critical successes of certain documentaries, including the previously mentioned *Fahrenheit 9/11*, *An Inconvenient Truth*, and *March of the Penguins* (Coffman, 2009, p. 62). Theories have been tossed back and forth by documentarians and researchers as to the increased interest. Paul Arthur (2005, p. 19) mentioned the presidential elections’ heightened media, emerging technologies, and nonstop cable news coverage as potential reasons. The reality television craze and the Internet have also been given as reasons for the increased interest for truth in images and movies, according to

Lynn Higgins (2005, p. 25). Even though most reality television is scripted, Lumpkin stated, “What it has done is make the notion of non-fiction much more respectable to audiences” (as cited in Puente, 2010). Furthermore, Higgins said, “In our post-9/11 historical moment, it seems to me that the stakes have been raised, reality has become ever more inaccessible, and the widespread hunger for images reflecting reliable information is correspondingly acute” (p. 27).

Documentaries can be used in many fields and arenas. Examples include using documentaries for educational purposes in schools and universities, medical education to teach empathy and humanity to future physicians, and at special events focused on certain social issues. In particular, Rabow et al. (2010) evaluated the educational value of using a documentary of family caregiving for patients with brain tumors. *The Caregivers*, directed by an award-winning documentary and educational film director and producer with knowledge and experience filming medical subjects (p. 243), was used to help enlighten neurosurgeons, neuro-oncologists, and other clinicians. The UCSF Department of Neurological Surgery and the Osher Center for Integrative Medicine collaborated with the filmmaker, Andy Abrahams Wilson, to portray the stories of four family caregivers of their adult loved ones who had a brain tumor. The researchers conducted a pre-post survey among the test groups who watched the documentary. Pre-test surveys showed that many clinicians held certain assumptions about family members who care for their loved ones. One assumption is that the family caregivers did not greatly influence the patient’s health. The other assumption was that support provided for these family caregivers was another person’s job, not that of the clinicians. Post-test results showed that those who watched the film were greatly impacted and stated their intentions to change their practice, provide more support for the family caregivers through social workers, and acknowledge that family caregivers indeed greatly influence the health of the patients.

As of late, the opportunities for documentary have increased in the television realm, through networks like PBS with their *Frontline* and P.O.V. programs, HBO's documentary channel, and the Sundance channel, all of which showcase documentary filmmaking. Documentaries also have a spot on many award festivals and events, such as the Academy Awards, Sundance Film Festival, and the Golden Globes, just to name three of the most well known. This genre of film has a strong and influential role in cinema and is relevant to use for spreading awareness and advocacy (Whiteman, 2007).

Documentaries for Social Change and Public Health

Documentaries have been a voice for people and causes for many years. Fraser (2011) said, "Few old things have flourished in the cultural chaos of this century, but docs have steadily consolidated their hold on a small portion of contemporary consciousness." Documentaries are constantly used as a storytelling form to spread awareness and promote change to improve current social issues. Trained documentarian Judith Helfand said, "The camera is a moral conscience, a reminder, a witness for history that we are not alone." (Aufderheide, 1998). Documentary filmmaker John Grierson sees documentary as "a solution that could close the gap between social problems and citizen understanding" (Kemmitt, 2007, p. 26). Documentary has also been termed by documentary scholar William Stott as a "social document...one that combines truth telling with human-interest storytelling (p. 26)."

One question always at the center of discussion between filmmakers, those involved in outreach, and researchers is whether documentaries make a social impact on the issue of focus. According to director Lucy Walker, audiences are expecting documentaries to be as impactful as fictional films (as cited in Puente, 2010). Nevertheless, researchers have a hard time measuring

the impact of documentaries on the social issues that are addressed (Puente, 2010). There is the level of success that can be measured with box offices numbers, counts of television programming viewers, and dollars the movies have earned. There are even recorded instances where a documentary has made a significant social impact, such as Errol Morris' *The Thin Blue Line*, which in 1988 helped rescind the conviction and death sentence of a man wrongfully convicted in the 1970s. Another example is the lesser-known 2008 movie, *Lioness*, about the first American female soldiers being placed in combat. This documentary aided in legislation allowing the soldiers to receive veterans' health benefits (Puente, 2010). These examples demonstrate the potential power documentaries can have over significant causes and issues, yet other documentaries also aid in promoting campaigns and raising money.

RX for Survival: A Global Health Challenge aired November 1-3, 2005 as a six-hour PBS television miniseries to both spread awareness about key issues in global health and support an outreach campaign, titled Rx for Child Survival, and to inform people in America on how to help meet basic needs of families and children around the world (Gore, 2005). The television miniseries and campaign also had partnerships with many organizations and companies, including The Merck Company Foundation, the Global Health Council, The United Nations Children's Fund (UNICEF), and even organizations like Rotary International and Girl Scouts of the USA. Many times, health networks will work with documentarians to create a film, like that of the Sugar Babies campaign, which raises awareness of the diabetes epidemic in children. The campaign hoped to raise money through their partnership with Alliance Health Networks and the documentary, also titled Sugar Babies, follows five families' stories ("Alliance Health," 2012). The Rx for Child Survival case is a specific example of how documentaries can make a difference and be used for social change. In August 2006, a year later after the campaign's

launch, \$85,577.57 was raised and given to the CARE and Save the Children child survival intervention projects in Nicaragua and Vietnam. During the campaign, nearly 300 events were collectively held by 21 community coalitions across the United States (RX for Survival, 2006). The Rx for Child Survival's website is still available for the public to visit and find organizations to which they can make donations.

Other channels that have helped bring awareness of disorders or diseases are the Sundance Channel and HBO Documentary channels. In 2008, Sundance Channel presented *Autism Every Day*, which spotlighted the lives of eight families struggling to raise children with autism, which also debuted at the 2007 Sundance Film Festival ("Sundance channel," 2008). The documentary aired on World Autism Awareness Day, on the same day that U.N. member nations sought to educate more about the disorder, for which diagnoses have increased over the last decade. HBO Documentary Films decided to place a spotlight on Alzheimer's disease in 2009 when it presented four documentaries, fifteen short supplemental films, website, and a nationwide outreach campaign in association with several health organizations ("Alzheimer's project," 2009).

Social change, especially regarding public health, does not have to be on a large or national scale. Sometimes a documentary can be set in a specific region and bring awareness people of that region. Broadcasted in Southern Nevada, *Crystal Darkness* was a documentary highlighting the state's meth problem and also part of a public education effort to educate viewers and call local communities to action. At the close of the program, Nevada provided a 2-1-1 number for viewers to call requesting more information on meth and assistance or referrals to treatment programs (Bach, 2007). Public health education can also begin as a book. In 2010, a

documentarian named Dianne Ouellette helped turn a book about postpartum depression into a 40-minute piece revolving around the three women who wrote the book (Roth, 2010).

Other ways to promote social change can excel through the form of news and advocacy journalism. A small, yet highly successful example is a local television news station in Mobile, Alabama coming together to produce pieces about a girl named Lauren Rainey. Although she was deaf, had asthma, had an enlarged heart, and had bone problems and scoliosis, she did not fit Medicaid's criteria to continue her 24-hour-a-day nursing care. The work of the station led to a team of lawyers with the Alabama Disabilities Advocacy Program to represent Lauren and get Medicaid to review and change their policy (Whitney, 2006).

One of the biggest reasons a documentarian will invest in a project to promote social change or raise awareness of health issues is the personal connection he or she has with the related subject. Physician and filmmaker Delaney Ruston created a documentary, titled *Unlisted: A Story of Schizophrenia*, to open viewers' eyes on people with schizophrenia and realize the effects any serious mental illness has on individuals and their families. In Ruston's case, she was at first estranged from her schizophrenic father, but realized the need to help him seek mental health treatment. Her story, which ended in tragedy after her father stopped taking his medicine and disappeared, became the emotional documentary titled *Father-Daughter* ("Father-Daughter," 2010).

In Whiteman's (2007) article, he describes documentarian Ellen Bruno and her small staff creating a film, *Sacrifice (1998)*, about human trafficking in Thailand and Burma. Part of the decision to create such a documentary stemmed from Bruno's background in international relief work and her extensive connections with specific people and organizations. As a result, *Sacrifice* made several impacts socially, individually, and politically. Human rights

organizations were able to freely use *Sacrifice* to raise money for their activities and projects in Thailand, as well as gain membership for the organizations. The film has also been used for training new volunteers and staff members for certain organizations. In addition, Bruno sent the documentary to political figures and insiders in order to get the message heard. Though these results did not provide great monetary rewards to Bruno, her goal of raising awareness of the particular issue was a success (Whiteman, 2007).

Despite all of this, however, media professor Patricia Aufderheide posited, “It is impossible to show scientifically that any single media event has a dispositive effect on events – that is just the sad reality of social science. That said, I think you can point to documentary films that have had a real-life, real-time effect in the world” (as cited in Puente, 2010). Whether the real-life, real-time effect is on a large scale or a smaller scale, the reason documentarians create movies about social issues is to have an impact on people, whether it be large or small.

Documentary filmmaking’s process

In most filmmaking processes, three stages exist: pre-production, production, and post-production (Jetnikoff, 2008a; Corbally, 2005; Swift, 2002). Pre-production refers to any of the activities that occur at the planning stage prior to any filming, said Corbally (2005, p. 377). Matoian (1982) compared the filmmaking process to the gestation and birth of a child. The pre-production involves the conception of the idea, including the creation of a final script. Then the kicking and stretching phase, which is the planning stage (p. 18). Within pre-production, Jetnikoff (2008a) stated that after selecting the topic, it is important to conduct some research about the central character(s) of the documentary. Jetnikoff stated, “Research might uncover an interesting newspaper article or news report, for instance, which puts a new angle on the character’s central concern” (p. 100). The next thing to do is design the story, starting with

framing the ‘central problem’ and finding the hook. The hook needs to grab the audience and take them on a journey. It also needs to answer the question: ‘how can I make the audience care about this character?’ (p. 100). Jetnikoff explained that it is best to conduct the interviews first, then collect images and visual material to fill in the story, as interview material alone becomes too boring to watch. Examples of visual material include still photographs, articles, archival footage, journals, and any other objects of interest or impact on the story. In Corbally’s (2005) study, student filmmakers agreed in advance on effects, like digital images (p. 377).

When it comes to planning for the production, it is important to already have assigned production roles before sequencing your story and developing a shooting schedule (Young, Gong, & Van der Stede, 2008). Jetnikoff uses another documentary filmmaker’s ‘dead fish metaphor’ to describe sequencing the documentary into three parts: Act 1 – what’s at stake?, Act 2 – thesis/antithesis, Act 3 – the tail winds up the end or relates back to the beginning. To save substantial production time, a schedule should be created to account for times and dates to shoot footage, locations, transport, props, equipment, and budget, as well as who is doing what on the different days of the shoot. Matoian (1982) stated this in-depth planning began the labor pains stage of filmmaking, since many negotiations and finalizations occur (p. 19). It is helpful to also make lists of other footage that could be shot on locations. Developing the style of the documentary can be thought about in pre-production. Some examples include the open/observational style, the cinema vérité style, and magical realism. When planning the interviews, it is vital to arrange the interviews beforehand with each central and additional person in the documentary. Every interviewee needs to sign release forms and anyone appearing in the documentary via images or footage needs to sign separate release forms as well. Then,

after confirming interviews and locations, the team should develop and hone the initial set of questions to ask all the interviewees (Jetnikoff, 2008a).

In a subsequent issue, Jetnikoff (2008b) discussed the aspects of the production and post-production stages of the overall production process. Production refers to all activities that involve actual recordings of audio-visual material (Corbally, 2005, p. 378). It is always a good idea to be flexible for minor changes and surprises occur, but the structured planning during the pre-production stage should help save time (Jetnikoff, 2008b). On the days of the shoot, secure all the equipment needed, including camera(s), tripod(s), spare camera batteries, external microphones, headphones, necessary cables, and the like. An important tip Jetnikoff gives suggests not sending interview questions to the participants beforehand as it may detract from spontaneity and authenticity. Pertaining to the location of the interview, she recommends visiting the subject and location in order to best light and compose the frame. Conducting the interview, one person can ask question, one can operate the camera, another can check one light, and another can work on sound (p. 64). When shooting the interview, it is helpful to do a one to two minute 'dummy run' by asking informal questions to put the subject at ease while checking sound and composition. Jetnikoff (2008b) offered ideas for the additional material to place around the interviews in a documentary. Examples consist of photographs or observation footage, which can include a subject's mannerisms or objects around a character, drama reconstruction, animation, archival footage or photos, recycled footage, location shoots like establishing shots, and abstract images (p. 67). Until you conduct the interviews and know what subjects have said, much of the additional material is hypothetical.

To complete Matoian's (1982) analogy in describing filmmaking, post-production is much like the delivery when giving birth to a child. All the work on set is complete, and now it

is up to a team including video editors, sound editors, and special effects personnel to fine-tune it, “making the baby presentable to its public” (p. 19). In Jetnikoff’s (2008b) section on post-production, she provides tips on capturing, organizing, and editing clips. When capturing video or footage, it is important to allow extra seconds on either side of the clip so no important information is lost. As the editor approaches his/her footage, it is critical to ask certain questions again. Some of Jetnikoff’s questions include: what is this story about? How do we develop and deliver the information and message and also maintain cohesion through image, narration and sounds? How will we deal with the dimension of time, when you have such a short space of time to tell your story? How do we create an emotional connection to the subject/topic? (p. 69). It is pivotal to match extra visual and audio content with what is said in the interview, in order to connect the material together and provide great way to illustrate what the subjects are talking about. Sometimes, in order to make sure the end product is clear, correct, and easy to follow, filmmakers must make decisions to re-shoot some sections (Corbally, 2005, p. 378). In her post-production section, Jetnikoff also discusses Developing a soundtrack, creating credits and titles, and outputting the project, both digitally and hard copy, are also parts of the post-production process (Jetnikoff, 2008a; Young et al., 2008).

Purpose of Creative Project

Many people in the United States and world have personal connections with at least one individual with an invisible illness or disease, yet people may be unaware. Just like Ruston’s documentary involving her ailing father, this author’s connection to Rachel is the inspiration for this documentary. The main purpose behind creating such a documentary is to raise awareness about invisible illnesses and educate people on the idea that anyone they meet could have an

invisible illness. The idea behind using documentary to promote change and awareness is to intertwine information and emotion as the two elements of ‘truth’ in the genre (Kemmitt, 2007). As Stott explained, “One knows another’s life because one feels it, one is informed – one sees – through one’s feelings” (as cited in Kemmitt, 2007).

METHODOLOGY

Pre-production

Producing the example segment of the larger concept was the most realistic option for this project. Normally, feature length documentaries hire large crews to serve multiple roles. Therefore, with one person serving in all positions, it would have taken a significant amount of time to complete a 60-minute documentary, more time than what was available. Since this author/producer acted alone in the production process, filling the roles of director, producer, camerawoman, and editor, producing a 10-15 minute segment made the most sense.

Choosing to showcase people living with invisible illness came about because of a family member who suffers with invisible illnesses. This led to selecting Rachel as the main subject of the example segment as she is the author/producer’s sister. Rachel Hale is a 19-year-old college student studying theatre at Cal Poly Pomona. The family members interviewed include her parents Peter and Bekah Hale and her younger sister Abigail Hale. Rachel is one of seven children, yet given the short time limit for the production, Abigail was the only one chosen for the sibling interview because of her availability. Abigail also has a particularly close relationship with Rachel, due to her heavy involvement with Rachel’s care. Friends and medical support interviewed include Dr. Brad Glenn, a practicing interventional radiologist and the inventor of the Invisiport, a device that when implanted into Rachel’s chest allows her to be able

to administer her own nutrition. Additional interviewees are her best friend Cameron Cerullo, her former nurses Karen Barnes and Dawn Pizzini, and UCSF Benioff Children's Hospital Executive Director Kim Scurr, as well as Art Therapist Suzanne Yau.

The personal connection to Rachel opened doors to contacts and provided easier access to medical facilities, as well as nurses and doctors. Healthcare is a sensitive domain, rife with privacy issues and patient protection. Knowing Rachel, who is a well-known patient within the University of California, San Francisco (UCSF) Benioff Children Hospital, came as an advantage. The process of building relationships and agreements with hospital administration, doctors, and nurses would have taken much longer had the connection with Rachel not existed. The producer previously had not met any of the medical staff and administration aforementioned before traveling to California and conducting interviews. Only interview dates and times were set. Releases were signed upon meeting for the interview. Familiarity with Rachel's family and friends also led to great access, making the process move more quickly. The producer is already family with the parents and Abigail Hale, but she also knew Cameron Cerullo. All of these reasons became the foundation for this project and aided the production and planning, as there was limited time to produce the segment. Other filmmakers, like the aforementioned Delaney Ruston with her film on schizophrenia and Ellen Bruno with her film on human trafficking, have used these types of reasons, especially the personal connection to the subject matter, as motivation for documenting the particular story ("Father-Daughter," 2010; Whiteman, 2007).

Rachel's story was set in California, primarily in the San Francisco and Los Angeles areas. The UCSF Benioff Children's Hospital is a significant location in the segment because it is where Rachel has spent a majority of her hospital time over the years. Cal Poly Pomona, where Rachel studies, and the Children's Hospital in Los Angeles were two other primary

locations, both of which are in the greater Los Angeles area. The segment is incorporates natural sound and footage to support the interviews. Photos and videos courtesy of Rachel and her family helped provide even more substance and reality to the overall integrity of the piece.

Pre-production planning of the segment involved working with the different schedules of every interviewee. In addition, because personal budget was used for traveling, as well as room and board, there was only one opportunity to travel to California and shoot the documentary. The amount of time devoted to shooting was about four days in San Francisco and three days in Los Angeles and Cal Poly Pomona, in Pomona, California. Considering Rachel's personal schedule, she was unable to travel from Los Angeles to San Francisco to conduct interviews in and around the UCSF Benioff Children's Hospital, the location where many of her worst and best memories with invisible illnesses occurred. Taking into consideration Jetnikoff's (2008a) issue on pre-production, a schedule was developed and included items such as dates, times, interviewees and their available time, and other footage that could be shot at each location. Since the producer did not visit all interview locations beforehand, she could only speculate the potential extra footage for each location. Using Matoian's (1982) analogy, the labor pains of filmmaking she experienced mainly comprised of the limited resources and time.

The style of the project's idea, as well as the produced segment, resembles that of a portraiture piece, focusing on individuals' stories. The segment, however, acts differently than other segments within the project idea as it involves personal narration. The personal connection between Rachel and the author is the primary reason for the author's personal narration of the piece. The need to disclaim the personal connection within the segment was of great importance in order to deliver transparency. The most affordable and natural way to undertake this was for the producer to personally narrate the segment.

Interview Material

Jetnikoff suggested research as important step in the pre-production process.

Researching invisible and chronic illnesses helped with background knowledge and perspective when it came to forming interview questions. Questions asked of the interviewees began with their definition and interpretation of “How do you explain what an invisible illness is?”

Questions to family members and close friends revolved around the beginning of Rachel’s illnesses, specifically the birth of her journey that led to the diagnosis of three rare and chronic illnesses. Other topics included the biggest hardships she has faced, how she has grown from these adversities, and how she has impacted her friends and family.

The first question asked of the medical support in Rachel’s life was, “How do you explain what an invisible illness is?” The next important question was to ask where they met first met and interacted with Rachel. Discussion covered how each person felt he or she has helped Rachel throughout her journey and with her independence, as well as how Rachel has impacted them.

Naturally, specific questions arose with those who had a specific reason for knowing Rachel. For example, since Dr. Brad Glenn invented the Invisiport, additional questions centered on how he developed the device and how it has impacted Rachel. As the first person ever to have the Invisiport implanted, Rachel has been able to live a more normal life (“Stealth Therapeutics,” 2012). It allows more freedom, yet also increases the invisibility of her illnesses. The Invisiport offers a minimally invasive, patient-friendly alternative to traditional chest ports and peripherally inserted central catheters (PICCs) (“Stealth Therapeutics,” 2012). Since Rachel needs long-term intravenous nutrition as a result of her Dysmotility syndrome, she had previously used seven different PICCs within 18 months. This increased the chance for

infection. The Invisiport combined the PICCs' ease of placement and the long-term advantage of a traditional chest port. As Rachel said in a press release for the product, "My Invisiport has allowed me to regain some of my freedom...[it] is so small that you can hardly tell that I have it. I can wear normal clothes and participate in more activities" ("Stealth Therapeutics," 2012). Both UCSF Benioff Children's Hospital Executive Director Kim Scurr and Art Therapist Suzanne Yau had experiences seeing Rachel become an inspiration to other patients and families in the hospital, as well as help with charities and events. These were helpful insights to Rachel's voyage throughout the last four and a half years.

Production

In reference to Jetnikoff's (2008b) text on the documentary production process, many of her general rules applied to small crews. Since the producer filled each role and production was one trip, certain items, such as scouting locations, was not doable. During production in California, there were both great successes and certain challenges. The first stop was San Francisco and the surrounding East Bay area, where the Hale family lived. In one production day, three interviews and additional footage of UCSF Benioff Children's Hospital were shot. The interview with Dawn Pizzini was conducted in the morning, additional footage was shot at the hospital, as well as the interview with Executive Director Kim Scurr, and the interview with Karen Barnes came in the evening. Although a busy day, all the shoots turned out successful. Because of each person's short amount of available time, only one location was shot for each interview, as well as once through the base list of questions. The next evening came the interview with Dr. Brad Glenn and two separate rooms were able to be used for interviews, allowing certain questions to be asked twice. The following day brought one more interview, with UCSF Art Therapist Suzanne Yau, and more time for extra footage at the hospital. Within

the UCSF Benioff Children's Hospital, everyone the producer met and worked with were extremely welcoming and accommodating. Moreover, since the producer is personally connected to the subject and family, it was natural for her to stay with family and enlist help from siblings to come on production shoots.

Another challenge arrived just before the trip to see Rachel at Cal Poly Pomona. Due to the busy schedules in the Hale family's life, there was only a window of approximately 20-30 minutes to interview Rachel's parents. This short window also resulted in having to shoot the interview at a public area, which is not the ideal location. The interview with Rachel's parents was a success. Although the location and framing were not ideal, the content of the parents' words were strong. The next challenge, however, was a bigger problem as it involved an interview falling through. A certain doctor who has been important in Rachel's earlier years with her invisible illnesses was considered for an interview. He knew much of her medical journey and according to Rachel and her mother, held a strong understanding of her conditions. Due to his reputation and recognition within the medical field, he often went out of state and his schedules were unpredictable. Potentially, the interview could be held over videoconference, yet even that proved difficult and it ended up not being possible with the short amount of time to complete videography on the project.

The last major challenge came with shooting a doctor's appointment of Rachel's at the Children's Hospital of Los Angeles. Since the hospital was not as familiar with Rachel and there were more healthcare and legal procedures involved, the challenge of handling paperwork and releases proved as a slight hindrance. These items must be finalized in pre-production, as much as possible, in order to make a smooth production process feasible and if had been done may have resulted in gaining access to shooting video at the doctor's appointment. The rest of the

interview and extra footage shot at Cal Poly Pomona went smoothly, as Rachel's professors were welcoming and helpful. The only disadvantage was the small amount of observational footage of Rachel because of the short amount of days at that location and Rachel's full schedule. Bekah Hale and Abigail Hale traveled with the producer to Cal Poly Pomona. Since Cameron Cerullo also attends Cal Poly Pomona, the interviews with Rachel, Abigail, and Cameron were shot during the days at the university. Overall, the producer wished for more additional footage, but it was a successful production.

Post-production

In the editing phase of the project, questions that Jetnikoff (2008b) suggested asking were useful in keeping on track while editing. Questions like 'How do we develop and deliver the information and message and also maintain cohesion through image, narration and sounds?' and 'How will we deal with the dimension of time, when you have such a short space of time to tell your story?' were important to keep in mind while incorporating still photographs, archival footage, and observational footage with the audio track from interviews.

A large majority of still photographs and archival footage, as well as the small amount of observational footage of Rachel, were obtained while visiting Rachel at Cal Poly Pomona. Since then, more still photographs were sent by Bekah Hale, mother of the subject, in order to add to Rachel's journey in the segment.

After logging and transferring the substantial amount of interview and supplemental footage to the computer, the producer began editing. Editing first involved reviewing and selecting clips with the strongest content. Jetnikoff's questions aided the process of narrowing down clips and editing the best sequence together. After assembling a rough cut of all the different interviews, adding the supplemental footage, archival footage, and still photographs

brought cohesion. Narration assisted in the cohesion, as well as in transitioning between passages of time. The decision for the producer to provide her voice for the narration stemmed from the direct sibling connection to the subject. Maintaining first person accounts of stories and struggles ensured a chance for emotional connection between potential viewers and the subject.

Close to finishing the segment, an opportunity arose to shoot some more observational footage of Rachel. Every few months, Rachel and Bekah Hale travel to the Nationwide Children's Hospital in Columbus, Ohio for appointments regarding a gastrointestinal pacemaker that was installed a little over a year and a half ago. The producer met with them in northern Indiana at a relative's home to visit and obtain any additional footage available of Rachel. This extra footage obtained after the production process was used to replace certain still photographs in order to enhance the visual storytelling of the segment. Just as Corbally (2005) mentioned in her article, sometimes re-shooting footage can ensure a stronger and clearer piece (p. 19).

RESULTS

Altogether, the production proved successful, as it tells the story of Rachel and her struggles, as well as triumphs, while living with three invisible illnesses. As with Rachel's story, the production process also had its challenges in addition to its successes. The challenges primarily existed within pre-production. Rachel was unable to visit her family during the 3-4 day shoot in the northern California area, due to her school schedule. Therefore, there could not be interviews conducted with Rachel at UCSF Benioff Children's Hospital, a sacrifice made as a result of limited options for traveling and interviewee schedules. This negatively impacted the end product since this hospital remains a vital part of Rachel's life. The service, doctors, and nurses from this hospital play a large role in Rachel's growth and triumphs. To work around this

disadvantage, shooting Rachel in a doctor's office or at a hospital was key to the credibility of the segment. Therefore, the arrangement with the Arcadia Center, part of the Children's Hospital of Los Angeles, allowed me to shoot video of Rachel at her doctor's appointment.

Another struggle in pre-production involved a failed set up of an interview with an important doctor in Rachel's story. This doctor was present during Rachel's early years to diagnose her illnesses and has become a close medical confidant. His desire to participate in the segment was evident. Nevertheless, due to the doctor's prominence in the medical field, his schedule and traveling to conferences did not allow for either an in-person interview or a videoconference interview. Using Dr. Brad Glenn for answering questions regarding Rachel's illnesses, in addition to his Invisiport development, provided a credible source for the segment.

Considering the one time opportunity to travel to California and shoot the documentary, the chance to visit locations and people prior to production caused problems. Extra time was included for each appointment to allow for finding the best spot for shooting the interview and equipment set up. In spite of this preplanning, some interviews had to be set up, conducted, and torn down in less than an hour. Improvisation and quick thinking became imperative with each interview.

BODY OF PROJECT

The project's video segment included interviews, personal narration from the author, additional footage shot in California, and videos and photos received by Rachel and her family. The transcription of the video, specifically the narration and interview content, may be found in Appendix A (page number).

Two outside evaluators add critiques and overall reviews to the body of the project. The first evaluator, Kathy Bruner, holds a title of Assistant Professor of Media Communication at Taylor University in Upland, Indiana. Her brief biography and evaluation is included in Appendix B (page number). The next evaluator, Terry Heifetz, is an instructor at Ball State University in the Telecommunications department. His brief biography and evaluation is included in Appendix C (page number).

SUMMARY AND IMPLICATIONS

Originally, the project idea and produced segment were going to focus on the topic of raising awareness of invisible illnesses and spotlighting specific individuals who struggle with their own invisible illnesses. After shooting the footage in California and upon editing the interviews, the original vision for the documentary shifted. The vision shifted from a strong focus on invisible illnesses to centering more on specific individuals and particularly how they have dealt with and continue to live with their illnesses. This shift in vision most likely stemmed from the questions and conversations with each interviewee. Taking the author's personal perspective and relationship with Rachel into consideration, it seems appropriate that the documentary should center on her specific story. That being said, it is in the author's opinion the segment turned out successful.

Nevertheless, not every step of the process during production went according to plan. Given the opportunity to recreate the segment, several things would be done differently. The first change would be to acquire more time in order to better develop the scripted questions and better schedule the interviewees. More time would allow additional interviews and longer or multiple sessions with each interviewee. The second change to increase budget would allow for

repeated flights to California, resulting in more footage of Rachel. Interviews of Rachel at the UCSF Benioff Children's Hospital and supplemental footage with her and family and friends would be far more feasible. Using increased budget and time would also allow the producer to bring on a crew to create the segment. A director and cinematographer would be mandatory to hire for the production.

The segment on Rachel's story serves the purpose in raising awareness of invisible illnesses and effectively shows that anyone that you meet could have an invisible illness. This purpose was achieved by providing an example of someone who, despite looking like a relatively healthy human being, deals with invisible illnesses on a daily basis.

REFERENCES

- Alliance Health Networks teams up with award-winning documentary filmmaker to raise awareness of diabetes epidemic in children. (2012, November 19). *Diabetes Week*.
- Alzheimer's project HBO Documentary puts spotlight on Alzheimer's disease; North Dakota family featured, The. (2009, April 30). *Mental Health Weekly Digest*.
- Arther, P. (2005). Extreme makeover: The changing face of documentary. *Cineaste*, 30(3), pp. 18-23.
- Aufderheide, P. (1998, October 23). The camera as conscience: How social issues inspire moving documentaries. *The Chronicle of Higher Education*, 49(5), B7.
- Bach, L. K. (2007, May 31). 'Crystal Darkness' documentary highlights state's meth problem. *Las Vegas Review-Journal*.
- Bauder, D. (2013, June 4). Ken Burns, Mukherjee collaborate on cancer documentary. *USA Today*. Retrieved from <http://www.usatoday.com/story/life/tv/2013/06/04/ken-burns-mukherjee-collaborate-on-cancer-documentary/2388627/>
- Coffman, E. (2009). Documentary and collaboration: Placing the camera in the community. *Journal of Film and Video*, 61(1), pp. 62-78. Retrieved from <http://www.jstor.org/stable/2068861>
- Corbally, M. A. (2005). Considering video production? Lessons learned from the production of a blood pressure measurement video. *Nurse Education in Practice*, 5, pp. 62-78. doi: 10.1016/j.nepr.2005.04.003
- Drumm, P. (2012, September 26, 2012). Stealth Therapeutics' Invisiport implanted in first patient. *Business Wire*. Retrieved from <http://www.businesswire.com/news/home/20120926005781/en/Stealth-Therapeutics%E2%80%99-Invisiport%E2%84%A2-Implanted-Patient>
- Father-Daughter story on schizophrenia is emotionally powerful; documentary will air on PBS stations; special screening at 2010 NAMI convention on July 2. (2010, July 5). *Mental Health Weekly Digest*.
- Fraser, N. (2011, March 19). Why documentaries matter. *The Observer*. Retrieved from <http://www.guardian.co.uk/tv-and-radio/2011/mar/20/documentaries-brian-cox-nick-fraser>
- Higgins, L. A. (2005). Documentary in an age of terror. *South Central Review*, 22(2), pp. 20-38. Retrieved from <http://www.jstor.org/stable/40039869>
- Horan, S. M., Martin, M. M., Smith, N., Schoo, M. Eidsness, M., & Johnson, A. (2009). Can we talk? How learning of an invisible illness impacts forecasted relational outcomes. *Communication Studies*, 60(1), pp. 66-81. doi: 10.1080/10510970802623625
- Jetnikoff, A. (2008a). Making a micro-documentary on a shoestring budget: Production & post-production. *Screen Education*, (51), 98-104.
- Jetnikoff, A. (2008b). Making a micro-documentary on a shoestring budget: Pre-production. *Screen Education*, (52), 62-71. Retrieved from Ball State University OneSearch.
- Kemmitt, A. (2007). Documentary stories for change: Viewing and producing immigrant narratives as social documents. *The Velvet Light Trap*, 60(1), pp. 25-36. http://muse.jhu.edu/journals/the_velvet_light_trap/v060/60.1kemmitt.html
- Gore, M. L. T. (2005). Rx for survival: A global health initiative. *Alternative Therapies in Health and Medicine*, 11(5), p. 23.

- Matheos, E., Vasileios, K., Ioannis, B., Dimitrios, Z., & Kostas, H. (2009). Superior Mesenteric Artery Syndrome. *Case Reports in Gastroenterology*, 3, pp. 156-161. doi: 10.1159/000209866
- Matoian, J. (1982). Book to film: The process explained. *Children's Literature Association Quarterly*, 7(3), pp. 17-19. doi: 10.1353/chq.0.0231
- NINDS Dysautonomia information page. (2011). *National Institute of Neurological Disorders and Stroke*. Retrieved from <http://www.ninds.nih.gov/disorders/dysautonomia/dysautonomia.htm>
- Public Broadcasting System. About us. (2013). *PBS*. Retrieved from <http://www.pbs.org/wgbh/pages/frontline/about-us/>
- Public Broadcasting System. P.O.V. (2013). Retrieved from <http://www.pbs.org/pov>
- Puente, M. (2010, September 22). Can documentaries save us?; Anticipated 'Waiting for Superman' looks at failing public schools. *USA Today*.
- Rabow, M.W., Goodman, S., Chang, S., Berger, M., & Folkman, S. (2010). Filming the family: A documentary film to educate clinicians about family caregivers of patients with brain tumors. *J Canc Educ*, 25, p. 242-246. doi: 10.1007/s13187-010-0105-y
- Roth, P. (2010, March 11). Postpartum depression book now a documentary. *The Leader-Post*, p. A-7.
- RX for survival. (2006). E-newsletter final edition: August, 2006. *PBS*. Retrieved from <http://www.pbs.org/wgbh/rxforsurvival/newsletter/archive/e-news-final.html>
- Schlachter, C. T. (2009). The New Transformation of the Public Sphere: Discourse through documentary. *Journal of Corporate Citizenship*, 36, pp. 87-97.
- Stealth Therapeutics' Invisiport™ implanted in first patient. (2012, September 26). *Business Wire*. Retrieved from <http://www.businesswire.com/news/home/20120926005781/en/Stealth-Therapeutics%E2%80%99-Invisiport%E2%84%A2-Implanted-Patient>
- Swift, Billie. (2002). On making movies. *Risk Management*, 9(1), p. 38.
- Sundance channel to premiere documentary Autism Every Day on world autism awareness day, April 2nd at 8:00pm et/pt." (2008, February 25). *Health & Medicine Week*.
- Understanding High Blood Pressure. (2013). *WebMD*. Retrieved from <http://www.webmd.com/hypertension-high-blood-pressure/guide/understanding-high-blood-pressure-basics>
- Whiteman, D. (2007). The evolving impact of documentary film: sacrifice and the rise of issue-centered outreach. *Post Script*, 26(3), p. 62.
- Whitney, D. (2006). For Lauren's sake. *Television Week*, 25(3), p. 55.
- Young, S.M., Gong, J.J., & Van der Stede, W.A. (2008). The business of making movies. *Strategic Finance*, 89(8), p. 26.

APPENDICES

APPENDIX A – VIDEO TRANSCRIPT

Narrator: At this California University, Rachel looks like any typical college
(:05-:24) freshman. She gets ready for her day and spends time with family and friends, even attends her theatre rehearsal. But Rachel is not the typical student she appears to be –

Rachel: (with smile/laughter) I don't think I could tell you how many times
(:25-30) people have told me, 'Well you look good, and I'm like, well thank you!'

Narrator: Rachel gets blood drawn once a week, routinely visits doctors.
(:31-1:13) Most importantly, Rachel has to administer her own nutrition through unusual means, since she is unable to fully digest food on her own. Everyday, Rachel continues to fight her invisible illnesses, while attempting to live out her life.

This is why I want to share the story of my sister Rachel, and her three rare and chronic invisible illnesses.

But first, how do you know somebody has an invisible illness?

Dr. Brad Glenn: Have you ever heard anybody complain about somebody who pulls
(1:14-1:34) into a handicap spot and they say, 'That person got out of that car and they walked right into the store, without a problem,' and their assumption in their mind is, 'That person's not sick.' It may not be extremely obvious from the outside that they have a disability, but it can really severely impact their life.

Rachel: It's not an exact science and no one except for me knows what
(1:35-1:51) goes on in my body, so it's really frustrating sometimes to try to explain what I'm dealing with, especially when no one can see it.

Narrator: Rachel's first illness is what's called Autonomic Instability.
(2:01-2:12) People's bodies normally regulate heart rate and blood pressure as they move around. Rachel's body, however, cannot do this.

Bekah Hale: She would stand up and just to walk across the room, her heart rate
(2:12-2:22) would jump to a hundred seventy, a hundred eighty, and obviously that comes with being dizzy and not being able to get around.

Narrator: Her second rare disease is referred to as Dysmotility Syndrome,
(2:24-2:33) which affects her ability to digest food, forcing her to use IV nutrition.

Dr. Brad Glenn: The nervous system is not firing properly, so this results in a
(2:33-2:48) dysfunctional intestine that can't do its job of propelling that food forward.

Rachel: Anytime I eat or put anything into my digestive system, it gives me
(2:48-3:03) nausea and sometimes pain. Nausea can be really debilitating, which is not easy to try to do active things when you sorta just want to curl up.

Narrator: Finally, her third and extremely rare disease is SMAS, short for
(3:03-3:21) Superior Mesenteric Artery Syndrome. Not only a mouthful to say, this rare syndrome is complicated and life threatening. The syndrome deals with the intestine and two major arteries in the body.

Dr. Brad Glenn: The intestine gets actually compressed physically by the two
(3:21-3:31) arteries, and it blocks the ability of food to pass through there.

Rachel: So like a lot of these symptoms just tire me out, like eating will tire
(3:31-3:50) me out sometimes cause it takes a toll on my body, just makes me
nauseous and makes me feel bad so I get, exhausted after I eat. It's like
Thanksgiving every day (laughs).

Bekah Hale: (sitting with Peter Hale) So when she first started talking, she was
(3:51-4:03) complaining of tummy pain and til she was about four and a half they
were trying to diagnosis what was wrong with this little girl and they
never could figure it out.

Peter Hale: She went through test after test after test after test and every time
(4:02-4:10) they come back and say, 'Well she doesn't have this, that's good news.
She doesn't have that, that's good news.' –

Bekah Hale: 'Everything looks good!'
(4:10)

Peter Hale: Oh yeah, that became one of the phrases which we would tend to
(4:11-4:18) not like. We want to know what's wrong.

Bekah Hale: But then by the time she was around seven, she did great until she
(4:17-4:24) was like fourteen and a half.

Peter Hale: And it came on suddenly.
(4:24-4:25)

Rachel: My brother's sixteenth birthday, and I woke up that night, at like
(4:27-4:36) three o'clock in the morning I think, with extreme pain and nausea.

Abigail Hale: One morning she's fine, but then that night we have no idea where
(4:36-4:41) it's coming from.

Rachel: After some time they finally took me to the ER, um, where it kind
(4:41-4:49) of all started.

Abigail Hale: And so it was really scary to see her like that and really frustrating
(4:49-5:01) because nobody was giving us straight answers, we couldn't figure out
what was going on, and nobody knew what was wrong with her.

Rachel: I think at that point it was a weird thing that was happening for that
(5:02-5:25) night. It was probably not until that December where I had lost, twenty
plus pounds, was lying there after doing tons of different tests and no one
could figure out what was wrong and like I wasn't getting better...going
okay, well, I'm in for the long haul.

Narrator: It took two and a half years for doctors to give Rachel a full
(5:26-5:36) diagnosis. Since her illnesses deal with an ability to eat, certain
assumptions, like eating disorders, came up during those years.

Bekah Hale: She continually had to, kinda prove, to people that that was not
(5:36-5:42) what was wrong.

Peter Hale: She's a foodie. She loves to eat. To where she'll work through the
(5:42-5:50) pain and nausea just to eat something that's good.

Karen Barnes: You could just tell, she was really feeling sick. But it wasn't
(5:50-6:11) anything that was so easy to do a test, this is what's wrong, and treat it and
fix her. We would try all these different things and it would be a different

level of not so bad or horrible. You know, it wasn't like she ever felt great. She was always in fairly great spirits, but you could see it in her face when she wasn't doing well.

Cameron Cerullo: She's very, very strong. Unfortunately, the flip side of that is
(6:12-6:32) never being open. The balance of, you know the fact that she does have to continue on, there's not another choice. At the same time, you have to let other people in on that and be on that journey with you. And that's really difficult to balance.

Bekah Hale: The things that stand out in my mind, actually, that are hard and
(6:33-7:30) will make me cry, are things like when she was just throwing up and throwing up and we couldn't figure things out (begins crying). She's this beautiful young girl who just wants to be normal and doesn't know what's going on with her body and; she had to let go of all her privacy, all the things that we kinda hide, you know, and I remember her sitting in the hospital bed, in a hospital gown, throwing up just so hard and Cameron's holding her hair, and it's the most unattractive, awful place to be in, and I just remember kind of stepping back and, being overwhelmed that she had to go through this, and so thankful she had the support to go through it that she did.

Rachel: (sitting with Cameron Cerullo) For me it's been nice to have
(7:30-7:54) someone who's constantly been there for me since I did lose my core base of friends. He's sort of taken it all in stride and helped me and encouraged me or made me laugh and been there when I was puking or whatever and

that's been an encouragement and really, really helped me through, some of my hardest times.

Cameron Cerullo: To be perfectly honest, a relationship that's not purposeful in situations like these really immediately falls apart, and that's exactly why all the other friends fell away because no one was willing to consciously make a stand, for and with Rachel.
(7:54-8:10)

Peter Hale: (sitting with Bekah Hale) Some of the other kids have gotten a bit stronger because of it, too. Because they had to, you know, step up; Abbie being one of them.
(8:11-8:17)

Bekah Hale: Our kids had to grow up fast, not just Rachel, all of them. All of a sudden, your perspective on life changes.
(8:17-8:23)

Narrator: Outside her family, Rachel's support also came from the medical staff she has bonded with over the years.
(8:24-8:29)

Karen Barnes: I know behind the scenes I fought for her a lot. You go to rounds everyday and you're the one presenting her case from the nursing standpoint and how she's doing and what she needs. So I did a lot of advocacy for her on that part.
(8:30-8:42)

Rachel: My nurses became my family. Not only would they get to know me for me, but they would also get to know me at my worst and my best, which is not something that a lot of people saw. And I would see them more than I would even see my family. They helped me grow, they became like mentors.
(8:43-9:03)

Narrator: What has also helped Rachel are unique and new medical devices,
(9:04-9:14) like the Invisiport, which is a central line that helps deliver her nutrition and gives her more independence.

Rachel: The Invisiport allowed me to be able to do everything myself. And
(9:15-9:44) it's under my skin, so I can take the needle out and I can go swimming and I can take showers normally and things I wasn't able to do before. So, [the needle's] actually in right now (touches her needle and Invisiport) cause I have to run stuff tonight. But I call myself Ironman when I have it on cause it's blue and it's round and it's in my chest, and, why not (laughs). So, I love having the Invisiport.

Kim Scurr: I love to see Rachel. I love that she's at college. I love that her
(9:45-10:07) family treats her completely like every other of their seven children. And nobody's got kid gloves on with her, but she doesn't need them, you know? She's just decided to make her own way, yeah I couldn't be more proud of her.

Rachel: It's tough, I kinda lead two lives in some way. I have my very
(10:07-10:22) medical life where I have to do all my medical stuff and I have to do sort of my normal life and college and family and friends and theatre, everything that I love.

Kim Scurr: She's made it not all about her, which is the initial reaction, right?
(10:22-10:52) What's happening with me, what's happening with my body? And now I think Rachel's like, 'Okay, this is what's happening, this is what I do to feel better, this is my job and my life, and now I'm going to go out and live it. But when her friends are struggling, she's right there with them because she knows what it's like to be in that bed and not feeling well.

Suzanne Yau: She has taken on this role of being a supporter and just a good
(10:52-11:16) friend to other teens that are going through a hospital experience, and it could be a very different medical diagnosis or similar, but she's just been really great at supporting other teens and helping them to feel empowered as well.

Rachel: I've had like a couple of little children that I've met in the hospital
(11:17-11:36) that I've gotten to know, as we're both in the hospital at the same time and I love sort of being there and being like a big sister to them. You cheer them up, and that's such a great thing to see when you're in a hospital setting.

Abigail Hale: It was actually through Rachel that I found that I love doing theatre
(11:37-11:58) and when she got sick, just seeing her still thriving to do what she had a passion for and also her strength in never giving up on anything has made me realize that I could have that same strength as long as I don't give up either.

Dr. Brad Glenn: (11:58-12:38) When they had learned about the Invisiport and they were thinking about possibly having that to provide her venous access needs, Rachel looked at me and she said, 'Look, I had a pacemaker placed for GI dysmotility, which has hardly been done at all. I see this and I see the advantages and this is something I want to do. It doesn't scare me.' And I think she's just an incredibly courageous young lady and very inspirational to me.

Rachel: (12:39-13:07) One of the greatest things I've gotten from this illness is my friendship with Monica. She's one of my best friends who actually is also dealing with something very, very similar, almost the exact same thing that I have. And together we've been through a lot and I was talking to her about it and we were like, 'Well why don't we just start a non-profit that helps kids and teens who are going through invisible illnesses, whatever those may be. And I'm really excited for that.'

Dawn Pizzini: (13:07-13:21) It's hard to say this because, she's kind of like, this incredible kid...who, you think, if I have a daughter someday, I want her to be, like that.

Kim Scurr: (13:22-14:28) Right before the holidays, she was laying in bed and Monica was there, and her mom, and your little sister. And I was sitting on the bed and they were showing me the video they were making. And Rachel just

reached over and took my hand while we watched it (begins tearing up).
Yeah, it was so, yeah, and I remember thinking while I was sitting there, I was like, nobody has a job like this. It's so great and it just made like going home and starting the holidays so much richer. I felt like I had had this, ridiculous gift! Uh, just handed to me. But I think I'm going to have so many more moments like that with Rachel that uh, I just think she's going to do great...I think she's going to do great...

APPENDIX B – MRS. KATHY BRUNER PROJECT CRITIQUE

I. Brief discussion of evaluator’s credentials (e.g., knowledge and experience of the subject area)

I am Assistant Professor of Media Communication at Taylor University in Upland, Indiana and co-chair of the Media Communication Department, comprised of majors in Film & Media Production, Journalism, Public Relations and Web Communication. I have taught video production in higher education since 1989 and have worked professionally as a corporate video producer and as a broadcaster at the Olympics in Sydney (2000) and Atlanta (1996). More recently I have executive produced fourteen short documentaries some of which have had film festival screenings and awards. One was the winner of a regional Emmy. I hold an M.A. in communication and a B.A. in broadcast-communication and journalism.

II. Relationship to the student and subject matter

Sarah Lu England was an undergraduate student in the media communication department at Taylor University for four years. I had Sarah as a student in several classes and also knew her as an exceptionally dedicated employee within the department.

I teach documentary production among other subjects and am therefore very familiar with the production methods that Sarah has employed in the process of making her creative project. I do not have expertise in public health or invisible illnesses.

III. Evaluation of the topic as appropriate for the creative endeavor

The topic is entirely appropriate for Sarah's creative endeavor in partial fulfillment of the M.A. degree in the department of journalism.

IV. Evaluation of the student's approach

Sarah's approach to the topic stems from her personal knowledge and close relationship with Rachel, the subject of the documentary. Combining an interest in public health with powerful storytelling, Sarah's project continues a trend of using short documentary to teach, inform and educate the public about diseases. The filmmaker's connection to the subject as sister emotional helps the audience gain entrance to this family and allows them to quickly develop empathy and appreciation for this remarkable young woman.

Sarah's literature review demonstrates familiarity with present and past trends in documentary filmmaking and its application to public health. Her methodology is sound and follows industry-standard practices for production. Sarah demonstrates understanding of the project's great potential as well as its limitations such as scope, budget, time and complexity when working with medical personnel and facilities.

V. Evaluation of the body of the project

a. Quality

Sarah's film project was particularly ambitious and attempted to cover a lot of ground in a short period of time. Given the time constraints, the resulting project is quite impressive. With more time, additional b-roll and footage from Rachel's daily life would have enhanced the story even more. Still, the quality of the project is certainly worthy of a graduate level creative project. Audio and video

quality are high, and the extensive use of still pictures and voice-over scripting demonstrates the major work effort that was involved. The end result is a compelling portrait of a courageous woman and the people who have helped her navigate difficult waters.

b. Depth of Treatment and Coverage

Sarah's documentary is thoughtfully constructed. It is no easy task to provide information about three little-known illnesses in the context of one 14 minute case study, but Sarah has done this admirably through the use of lower third graphics, voice-over narration and carefully edited expert interviews. The audience learns a great deal and also gains empathy for people with invisible illnesses. While the illnesses are not explained in extremely detailed form, such depth would be inappropriate for this artform. Documentary always must ride the line between educating the audience about the unfamiliar without losing them in complexity.

VI. Evaluation of the student's work as contributing to the field (e.g., body of knowledge)

Sarah's documentary makes an excellent contribution to the field of invisible illnesses, quite literally 'making visible' in documentary form the health challenges that those around us face every day. I can imagine Rachel's doctors and nurses eagerly using this story to encourage other patients, especially children and teens. Patients who suffer from one or more of these diseases may find courage in Rachel's story and parents likewise may take heart in hearing the story of Rachel's parents' journey. The support organizations for these illnesses would also benefit from

providing a link to the story from their websites and newsletters. Sarah has definitely made a notable contribution to health education by means of compelling storytelling.

APPENDIX C – MR. TERRY HEIFETZ PROJECT CRITIQUE

I. Brief discussion of evaluator’s credentials (e.g., knowledge and experience of the subject area)

Terry Heifetz is an Instructor of Telecommunications at Ball State University, teaching courses in news writing, reporting and producing. He has taught two classes that have produced documentaries; one class won a regional Emmy in 2011 for its work. He is also news director of Indiana Public Radio (WBST) and news consultant to student radio station WCRD. Before joining Ball State, he worked in producing and management positions in local and network television.

II. Relationship to the student and subject matter

Terry Heifetz worked with Sarah Lu England on the 2012 SUSI project, a U.S. Department of State grant that brought 20 international students to Ball State University over the summer. They have also worked together while Sarah was the graduate assistant at the Integrated Media Lab at Ball State.

III. Evaluation of the topic as appropriate for the creative endeavor

This topic is completely appropriate for a creative endeavor. Sarah Lu embraced an issue that few people ever think about and produced a documentary segment that is informative, compelling, and personal. I can imagine that this would be a topic and approach that would interest mainstream documentary programs such as Frontline.

IV. Evaluation of the student’s approach

Sarah Lu took a topic and subject that are personal to her and turned them into a high-quality documentary segment. She could have approached this story in other ways; she could have written a long-form story or used other journalistic methods for

storytelling. However, since she is so close to the story, a documentary is the best approach. Documentaries do not have some of the restrictions that a typical news story has. In most news stories, the reporter cannot have a close connection to the people in that story. However, in documentaries, it is almost expected that the storyteller has a connection and point of view. Documentaries also enable a storyteller to use emotion in an effective way. The video and audio convey the sadness and happiness in ways that the written word typically cannot. Sarah Lu made an excellent choice by producing a documentary segment to tell this story.

V. Evaluation of the body of the project

a. Quality

For me, one of the better tests of the quality of a student project is simple; does it hold my interest? In this case, the answer is very clear. I watched the entire 15-minute segment without checking the time or getting bored or distracted. Sarah Lu captured an emotional story and produced it with elements that helped tell it well. Not only were there good sound bites and video, she used still photos, natural sound and b-roll to help the viewer feel a connection. The project is not perfect. You see microphone cables. The lighting could be better. However, her paper that accompanied the project stated it best. Sarah Lu was basically what we would call a “one-man band.” She did it all and had to shoot the piece in a short period of time. A professional would have had weeks to do what she did in days. Considering the constraints she faced, Sarah Lu did an exceptional job. Did the technical imperfections affect the storytelling? No they didn’t. The story was clear.

b. Depth of Treatment

This piece had a balanced approach. It was part technical and part emotional. The audience gets enough information about the medical conditions that the story didn't get lost in all of the jargon and technical terms that come up throughout the piece. But the story really keeps the audience interested with its cast of characters. You have the protagonist, the patient suffering from the illness. You have the rest of the cast, including family, friends, doctors and nurses. They combine stories of their personal struggles against the illness and the overall situation. The segment does an excellent job of enlightening the audience about a problem that is largely ignored. It is covered in a way that is interesting and informative.

c. Coverage

d. Sarah Lu covered this story in the best possible way for a documentary. For the most part, she let the characters do the talking. She spoke when necessary. She set-up the issues, the characters, and the plot. Then, she got out of the way and let the story tell itself. When something needed further explanation, she re-entered the story with her narration. As the main character's sister, Sarah Lu also inserted herself into the segment when needed, but not too much. It just helped establish the connection between the two.

VI. Evaluation of the student's work as contributing to the field (e.g., body of knowledge)

Sarah Lu England covered a topic that is invisible to most people and brought it into the spotlight. In her paper, she justified why this is a topic that deserves coverage;

only people directly affected by invisible illnesses may realize they exist. In the project, itself, she demonstrated what she stated. She showed why it is important for the general public to be aware of these issues. There are stories to tell. One part of the segment made a significant impact for me. The sound bites explaining what happens when people see drivers they think are able-bodied using handicapped parking spaces summed up the big picture. In reality, you cannot always see serious illness with the naked eye. When the anecdotal evidence was combined with the expertise of medical professionals, the segment made its point. Sarah Lu followed the best practices discovered in the literature to share her sister's story by producing a documentary segment that informs and educates. She used the techniques she researched about the steps needed to create a high-quality documentary. And her research showed there have been few documentaries produced that tackle the topic of invisible illnesses. Therefore, by creating this segment, she effectively advanced the body of knowledge in the field.