

KEREN

by

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A thesis submitted in partial fulfillment of the requirements
for the degree of Master of Fine Arts
in the School of Visual Arts and Design
in the College of Arts and Humanities
at the University of Central Florida
Orlando, Florida

Spring Term
2014

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ABSTRACT

The intent of this thesis is to recognize the everyday victories of a child living with physical disabilities. This complicated subject matter has forced the exploration of a variety of media to successfully communicate the story; drawing, painting, china painting, altered books and sculpture have all become part of the process.

At the age of 8 months the subject, Keren Hernandez, was diagnosed with Bilateral Closed-lip Schizencephaly, a rare disorder that inhibits development. Since the diagnosis seven years ago her family has struggled to overcome these challenges, committing to avail themselves to every resource possible. I began painting and drawing to incorporate the experiences of Keren's life into a body of work; eventually we began drawing together and collaboration has naturally evolved; she and her family are an integral part of this work.

This paper is dedicated to my son, Noah Bradon, a man of large vision,
and to my parents, who taught me to pursue my dreams.

ACKNOWLEDGMENTS

I must acknowledge my family and my friends, in particular Dina and Dan Hernandez. Without their support and encouragement, the fulfillment of this dream would have been impossible.

Many thanks to the members of my committee, Carla Poindexter, Larry Cooper, Mark Price, and David Isenhour. Your guidance and assistance has been greatly beneficial to the construction of this paper and the corresponding work.

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INTRODUCTION

As far back as I can remember drawing has been a first response to all of life - emotional, intellectual or spiritual stimulation -- or the lack of any of the aforementioned. Drawing is entertainment, communication, and solace. I feel an affinity with artists such as George Rouault, who felt compelled to speak up for the fringe members of society, while constantly doubting his success at doing so. I was moved and inspired by the work of Diane Arbus, her poignant photographs of street kids and carnies. She transcended documentation to create in me a desire to know more, as Gauguin did when returning to France laden with exotic paintings of Tahitians.

I saw an exhibition of the figurative work of Jenny Saville and was deeply impacted by her large scale paintings and luscious application of paint. This inspired me to investigate some aspect of the human form; I do not find “beautiful” people interesting as subject matter, and I love to work large. Intrigued, I completed a 10 - foot square monochromatic study in oils of an infant’s cleft palette, and then a smaller study of another. My subject matter was peculiar, to many it was grotesque, but I was investigating making beautiful paintings of ‘unbeautiful’ subject matter.



Figure 1: *Untitled*, by Author, 2012, Oils, 10 feet x 10 feet



Figure 2: *Untitled*, by Author, 2012, Oils, 30 inches x 36 inches

As a result of the above (Fig. 1 and Fig. 2) I continued my investigation of materials and subject matter, including a contemporary approach to portraiture. I was introduced to china painting by a friend about seven years ago and wanted to explore the quality of the medium and

see if it satisfied the images I had in my mind. I was inspired by *Side Show*, a fall production of the UCF theatre group based on the lives of the Siamese twins Violet and Daisy Hilton. The Hilton twins were born in 1908 in England and adopted by a couple who saw the potential for commercially marketing them (Jensen, 13). Their careers began in a traveling sideshow carnival at the age of three. They were brought to America where they became vaudeville performers, and acted in the 1932 film *Freaks* and the 1951 film *Chained for Life*. I was reminded of the work of Diane Arbus and saw the potential of using the porcelain and ink process. I chose to depict contemporary tattooed subjects to reference the idea of a “freak” show. The piece became a seminal influence in my current studio practice.



Figure 3: *Side Show*, by Author, 2012, Porcelain ink, premade porcelain vase, 7” x 8” x 5”

In the year 2000 my husband was diagnosed with pancreatic cancer, one of the most painful types of cancer known. The pancreas produces the enzymes the body requires to break

down and metabolize the food it consumes, as well as the insulin it needs to avoid diabetes. Rick endured two major surgeries, but by the time they found the tumor the cancer had spread, extinguishing any hope of survival. Due to the nature of his cancer, he suffered an enormous amount of pain and starved to death over a period of six months. Eventually he became completely physically dependent on me; we were inseparable during this period.

I tried to find a way to express what it was like to lose someone you have spent your entire adult life with. I eventually settled on the analogy of amputation; the limb is gone, but life goes on, and although you will never be the same, you adjust to accommodate this disability. I have heard stories of people who have experienced the loss of a limb yet can still feel its presence, a phenomenon known as phantom limb (“Phantom Pain”). In researching amputation I discovered there are people who have paid to have healthy limbs removed. Unsatisfied with a fully functional, normal body they intentionally and drastically alter their bodies, a condition referred to as BIID (Body Integrity Identity Disorder) (Levy, 75-86). During my research for subject matter for the *Side Show* piece, I came full circle to a group of people who had spent a great deal of thought, money and time to having their bodies altered. Included were people in pursuit of what they considered physical perfection....Ken and Barbie doll lookalikes, Manga character lookalikes, perfect noses and larger breasts; creating work about this particular group of people held no interest for me, although it is an ever-growing segment of our society. My interest was more broadly based on the idea of loss in its many forms. I began formulating a body of work based on the loose working title, “Less Than Perfect”. My research lead me from one subgroup to another, from people who had been heavily tattooed and pierced, to people whose bodies had been altered as a form of punishment, such as in Sharia law, or subjugation of a group of people by rebel groups such as the LRA in Sierra Leone. I created a series of porcelain pieces addressing this subject

matter, beginning with a further investigation of heavily tattooed and altered people, and victims of Sharia law.



Figure 4: *Piercing and Tattoos, a Collection*, by Author, 2012, Porcelain ink, porcelain pieces



Figure 5: *Sharia Law, a Collection*, by Author, 2012, Porcelain ink, premade porcelain pieces

I made a conscious decision to use pre-made porcelain pieces for this body of work. A correlation may be found in the way I have altered these premade pieces for my own esthetic ideas, similar to the way people may choose to physically alter their own bodies to match their ideals. I felt that using ordinary objects for extraordinary subject matter was a more effective way to address the jarring shift in these people's lives. Working only in black-and-white was also intentional; I wanted to create a visual consistency in the pieces and keep the focus on the subject matter and not my technique.

The content of this body of work led me to people who were born with severe birth defects and people whose appearances had been altered due to accident or illness.



Figure 6: *Birth Defects and Illness, a Collection*, by Author, 2012, Porcelain ink, premade porcelain pieces

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Influenced by the Cabinets of Curiosities used to display collections of biological and botanical oddities and wonders (moma.com), as well as by Damien Hirst's Cabinet series, I began keeping these black-and-white porcelain pieces in a simple glass cabinet. The effect was striking, drawing attention to both the strengths and weaknesses of the pieces. Some of the porcelain objects are a natural fit for the subject due to their utilitarian nature, or the shape or the object reflects an aspect of the subject matter. Some of the earlier pieces have an air of superficiality, a

more decorative approach than others do. The enclosed glass case and close proximity of the pieces invites closer inspection.



Figure 7: *Cabinet of Curiosities*, by Author, 2013, Premade porcelain, ink, glass, aluminum, 6' x 18" x 18"

The more I read about the people whose personal stories affected me, the more responsible I felt about how I represented them, how I told their story. Although Judy Chicago's *Dinner Party* was not the inspiration for my next piece, I am certainly aware of its relevance for

me. There is a parable in the Gospels that tells the story of a wealthy man who threw a wedding feast for his son and bride (Matt 22.1-14). He invited his friends and all the important people in the town, who politely made excuses why they could not attend. The ruler sent his servants out to lesser acquaintances, who also chose not to attend. Finally, the great hall was filled with all the misfits and poor of the community. It was this parable, this recognition of the fringe members of society that led my thoughts to my dinner plate series, each place setting representing a different subgroup that I had encountered: those who were altered by choice, those altered forcibly by others, those altered by illness, or by birth defects and war. In this parable, it is everyday people like me who become the guests at this banquet of grace.







Figure 8: *The Wedding Feast*, by Author, 2013, Premade porcelain, porcelain ink. 18" x 6"

Recently I was challenged to narrow my subject matter and made aware of the magnitude of material a body of work with so many individual subjects could encompass. How was I connected to these people? Did I know them? How could I be their voice? My attitude seemed to undermine the people I wished to be an advocate for. I was advised to address my own absence from this imagery; this thread had been noted by others over the past two years. I believe my existential absence mirrors their sense of loss, their longing to belong somewhere.

Narrowing my subject to one group was made easier in light of my personal involvement with one particular child.

KEREN

I have known Keren Hernandez for her entire life, and I had known her parents for many years before they adopted her. If someone is not able to have children, he or she will be able to more easily identify with the struggles involved in the adoption process. Any child is a miracle, to have the double blessing of adopting a child is breathtaking.

Keren was a beautiful and happy infant. Her parents did not notice any significant physical developments until she was six or seven months old. Because she was their second child, they noticed that she seemed late in some physical developments, such as being able to sit up straight, but they blamed it on her chubbiness. In her 8th month they began discussing their concerns with Keren's pediatrician, who recommended an MRI. The results were immediate and conclusive. Keren was diagnosed with Bilateral Close-lip Schizencephaly:

A rare developmental disorder characterized by abnormal clefts, or slits, in the brain's cerebral hemispheres. Persons with Schizencephaly may present with varying degrees of developmental delays, seizures, delayed speech & language skill, and vision & eating disorders. Many have normal intelligence. (Wright)

In my research I was introduced to the philosopher Maurice Merleau-Ponty and his writing on Phenomenology. I was fascinated by his discussion of the human body in its relation to the issues that Keren has faced in light of her Schizencephaly. "We grasp external space through our bodily situation. A "corporeal or postural schema" gives us at every moment a global, practical, and implicit notion of the relation between our body and things, of our hold on them. A system of

possible movements, or “motor projects,” radiates from us to our environment.” (*The Primacy of Perception*, Merleau-Ponty) Keren’s awareness of physical presence, her ability to navigate the corporeal world was greatly challenged. Immediately following her diagnosis Keren began a daily regimen of Physical Therapy and Occupational Therapy; her parents became consumed with the daunting task of helping Keren catch up with months of delayed development.

A few months ago I visited Keren’s mom, who is a friend, and I drew animals with Keren from a step-by-step book. It was such an enjoyable experience for both of us that we began drawing together more and more, progressing from drawing side-by-side to collaborative work. She is a typical eight-year-old emotionally and intellectually, funny and self-confident. During the process of working together and talking with her, I began to realize that she does not regard herself as different. It has revolutionized my thoughts, making me take a hard look at how society perceives someone who is physically handicapped. I began researching and found her attitude to be typical. “The question one must raise is not why do some children with cerebral palsy or spina bifida develop emotional difficulties but why is it that so many of them do not (Fox).”

I wanted to make artwork about Keren. Once again I used porcelain, the medium I had found successful for my visual storytelling. I had a tall graceful vase that was reflective of the movement I saw in Keren’s body when she was able for the first time, at the age of three, to put her hands over her head. It was important not to just decorate this vase, but to include visual information all the way around the vase to enhance its sculptural aspects. I struggled with the piece until I began drawing with Keren. It was then, in one of her drawings, that I saw her hands completing this piece (Fig. 10). She loves drawing happy faces and hearts, and hearts with happy faces, and I saw her hands formed by the shape of the heart she had drawn.

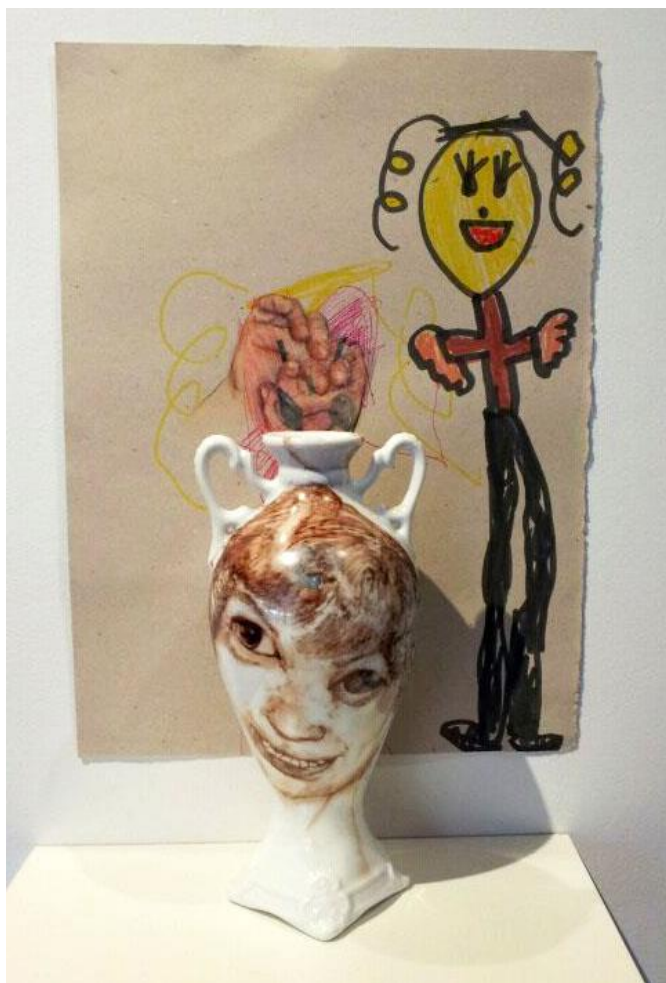


Figure 9: *So Big*, by Author, 2013, Porcelain, ink, china paint, acrylics, markers. 24" x 14"

I felt compelled to execute a portrait of this beautiful child and her classic beauty, with her curly blonde hair, blue eyes and a ready smile that wins people's hearts in a glance. But for me her mind and development issues were so palpable that I had to address them in my work. When I began the piece, it was a continuing exploration of the plate/portrait series from the previous year. I used only pre-made china plates, saucers, and accessories. I wanted to interrupt the representation of Keren's portrait to mirror some of the challenges she faces in her development. My initial artistic effort was unsatisfactory; the imagery became secondary to the form of the china

pieces, diverting the attention from content to form. I was able to resolve this by adding the broken fragments of the image to a traditionally completed portrait, interrupting my audience's ability to observe the painting without effort (Fig. 11).

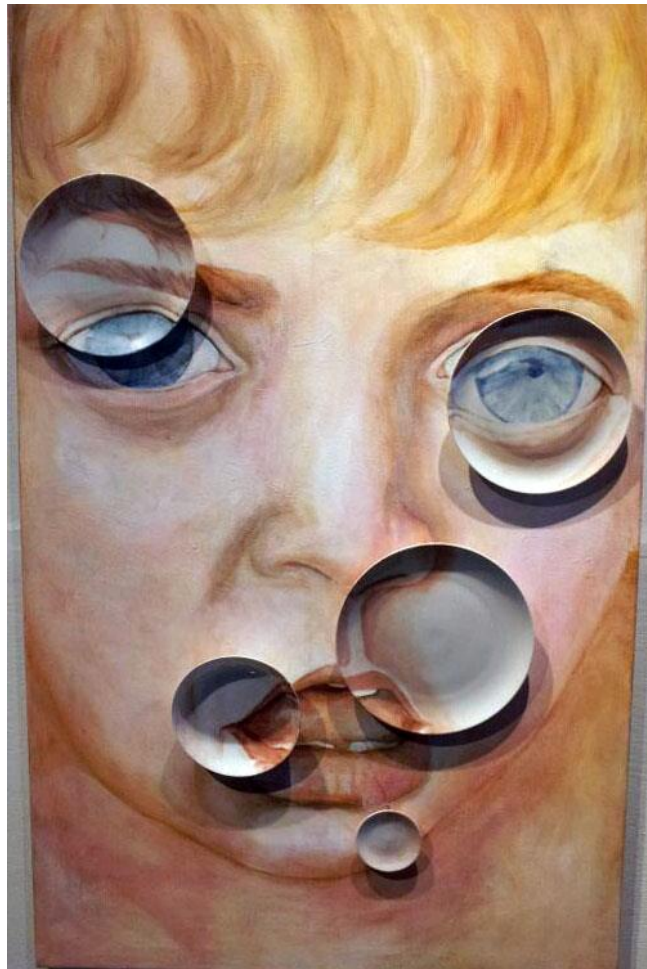


Figure 10: *Keren*, by Author, 2013, Canvas, acrylics, porcelain, china paint. 30" x 36"

While creating this work I discovered the art of Julian Schnabel and his use of porcelain plates as a medium. Schnabel applies broken china pieces onto his canvas as part of his initial preparation of his painting surface. My approach was to use the porcelain pieces as the only

substrate, adding the canvas background later. This approach was a further attempt to break the boundaries set by my earlier porcelain pieces “The Wedding Feast” the year before early in 2013.

Keren enjoys seeing pictures of herself, and it was easy to enlist her help when I began executing portraits of her. I was intrigued by her understanding of proportion and scale, especially when she completed drawing her body in the infant stage (Fig. 12). She is very specific about the way she draws the color of her hair and eyes, and the way she designs braids, her curls, and details such as the patterns in lace-up shoes.



Figure 11: *(Self) Portrait Series*, by Author and Keren Hernandez, 2013, Acrylics, Marker, Color pencil. 18" x 60"

During my research process for Schizencephaly my mind kept replaying the conversations with Keren’s parents during the weeks after her diagnosis; there was a numbness associated with the realization of what it would mean in her life, and theirs. I wanted to communicate the shift in thought process required for them at this point, and I felt compelled to create a work that demonstrated the idea of layers of revelation following the unexpected results of her MRI. What was expected was the standard scenario discussed in such books as “*Your Child’s First Year*”.

The artwork that emerged became an altered book based on *Baby's First Year* (Fig. 13). I went through the first months of this volume and made notes about Keren by referencing her mother's timeline. It was in her 8th month that the first MRI was run, and this is where I began cutting away the pages, interrupting the natural flow of information. It was important to me to create an arresting visual representation of what had confronted the family, simultaneously giving the viewer as much information as possible.

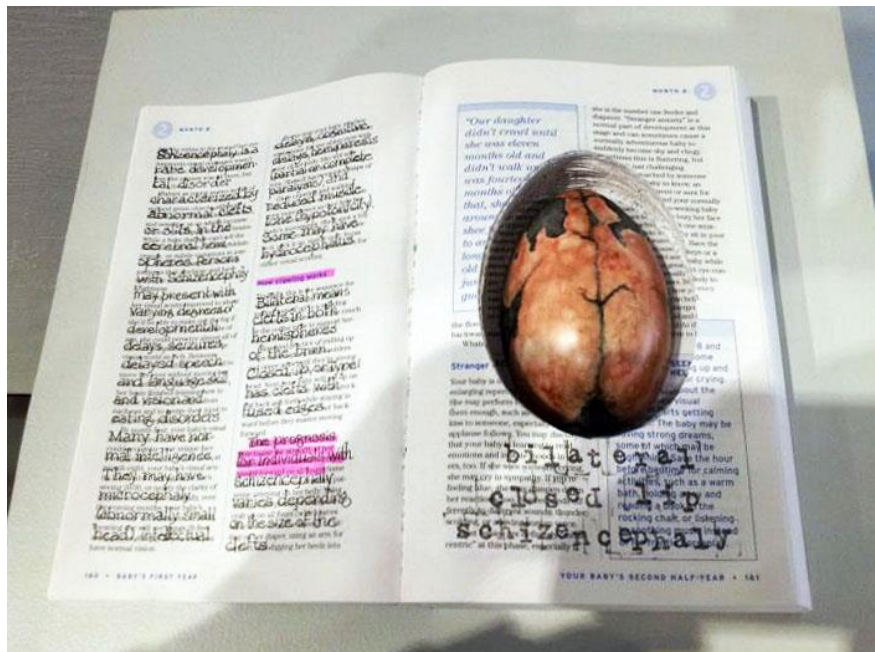


Figure 12: *Baby's First Year*, 2013, Altered book, porcelain, porcelain paint, ink. 15" x 9" x 3"

After Keren began her daily regimen of physical and occupational therapy, it took 14 months before there was significant physical development. At 21 months of age, when most children have been walking for six months, Keren crawled for the first time. The physical weight and size of this piece (Fig. 14), patterned after a Tibetan sketchbook, is my interpretation of the day-to-day experience of her parents as they drove back and forth, carried her and worked with her at therapy sessions. The time span represented by the book is from her eighth month until she was

21 months old, approximately 425 days, each page represents one day recording no changes. The outside of the book is decorated in a technique requiring many hours of repeated pattern, representing the daily ritual of physical and occupational therapy. All the pages are necessary to complete the image, just as all the days of Keren's (and her parents) work and endurance were required in order to achieve success.



Figure 13: *Everything Has Changed*, by Author, 2014, Wood, paper, acrylics, ink. 11" x 17" x 7"

At 3 ½ years, Keren achieved the remarkable feat of using a walker, freeing her from heavy dependency on family and friends. Although she still needed help, watching her propel across a room, racing to play with other children, was like watching a child who had just learned to ride a bike with no training wheels; sheer joy and a feeling of freedom and independence! Playing with the classic tales of Hermes and Icarus, and employing wings to represent the freedom Keren was

now achieving, I created a piece to portray this idea with an actual walker (Fig. 15), which was simultaneously tangible evidence of her handicap and of her independence. By suspending the front section of the walker off the floor, I suggested that Keren was about to take flight.



Figure 14: *Walker*, by Author, 2013, Aluminum, rubber, plastic, feathers. 36" x 36" x 30"

CONCLUSION

Everything that happens in one's life affects other things. Navigating public places with my husband in a wheelchair, having to take him in to men's bathrooms because of limited family bathroom access, made me more sensitive to all handicapped peoples' access to public bathrooms, stairs, sidewalks, and aisles in stores. So did the kindness of strangers in unexpected ways – young tattooed teenage boys who would hurry ahead to open doors, elderly people who would give deference when they saw my husbands' need to use the restroom or be attended to. We were unable to have our own children and going through the adoption process greatly affected my sensitivity to everyone involved in the adoption process – young mothers who choose to give birth and release their babies, parents in hardship cases who give up their children, the adoptive families, and the children and orphans themselves.

Relationships and our humanity figure prominently in my work. I will not stop working with Keren just because my thesis is complete; she is a family friend and I look forward to watching as she grows into a young woman, full of joy and anticipation of what life will hold for her. I feel the same way about myself and my own work; I have years of exploration ahead of me. Compared with many graduate students, I am old, but years of accumulated experiences inform my work and compel me to remain disciplined in my studio practice. The three years in graduate school have solidified my focus on my work. I must dig deeper and work harder than ever before. It is the passing of time that makes me realize how precious time is.

APPENDIX

IRB APPROVAL LETTER



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901, 407-882-2012 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

From : **UCF Institutional Review Board #1
FWA00000351, IRB00001138**

To : **Shelly Bradon**

Date : **March 12, 2014**

Dear Researcher:

On 3/12/2014 the IRB determined that the following proposed activity is not human research as defined by DHHS regulations at 45 CFR 46 or FDA regulations at 21 CFR 50/56:

Type of Review: Not Human Research Determination
Project Title: MFA Thesis for Shelly Bradon
Investigator: Shelly Bradon
IRB ID: SBE-14-10149
Funding Agency:
Grant Title:
Research ID: n/a

University of Central Florida IRB review and approval is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are to be made and there are questions about whether these activities are research involving human subjects, please contact the IRB office to discuss the proposed changes.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 03/12/2014 11:37:51 AM EST

A handwritten signature in black ink that reads "Joanne Muratori".

IRB Coordinator

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