

**RESPONDING TO MS THROUGH SONG:
A RESEARCH-CREATION PROJECT**

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BMus, University of Lethbridge, 2013**

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DEDICATION

For Kim

ABSTRACT

After receiving an earth-shattering Multiple Sclerosis diagnosis in 2019, I sought to find other musicians living with the disease who would share their stories, voices, and music with me. In May 2023 vocal ensembles *JamChor*, and *Nerve Damage*, took to the stage at the University of Lethbridge to present a collection of music that became significant in representing my version of MS. In this live performance piece, the audience experienced music by Jeff Beal, Art Alexakis, Britt Quiroz, Eric Whitacre, and The Wailin' Jennys. Interview footage was injected between musical numbers. Singers and composers living with MS discussed diagnosis, disease-modifying drugs, disability, symptoms, and music. A supplementary file containing the full live performance is available for viewing. This performance acted as a platform for those living with a chronic autoimmune disease to speak for themselves and removed all sense of medicalization. The human voice was the central focus of the work, and each participant used their voices as advocates, teachers, and musicians. Although my story was an integral piece of this puzzle, I felt grateful to each participant for allowing me insight into their lives. Many of our conversations focused on difficult topics regarding each person's arduous journey with Multiple Sclerosis; however, it was in discussing music that each participant agreed that singing, composing, and listening to music created a sense of catharsis and healing.

ACKNOWLEDGEMENTS

I am grateful to those who have supported this journey in both my life as someone living with Multiple Sclerosis and as a singer and researcher.

My committee members Monique, Mia, and Janet have encouraged and supported this research-creation project since day one. Their energy has guided and motivated me to structure this project in a way that was meaningful to me as an artist.

I am forever indebted to my voice teacher, mentor, and supervisor, Dr. Janet Youngdahl, who has shown me patience and understanding as we worked together to re-learn this instrument of mine. Upon diagnosis, my biggest fear was losing the ability to sing. Throughout this project, you have encouraged me, accepted the challenges, and provided patience and kindness. Our time together has been a gift to me.

The support of my family has been crucial in leading me to where I am today as a singer, researcher, and professional. From the first time I expressed my desire to sing, they encouraged it. I am grateful for always being able to follow my path. It has led me to amazing opportunities, and I am so lucky that they have never missed a performance.

Jack, Penelope, and my sweet Ollie: thank you for keeping me company during long study nights. Meow.

I would be remiss if I did not acknowledge the fabulous people who joined me on stage and behind the scenes to make this project what it was. Without you, it quite literally would not have been possible. Noelle, Rosie, Julena, Randi, Tiffany, Isaac, Bryce, Adam, Franz, TanTan, Carson, Dacs, Britt, Art, Jeff, Kathryn, Chris, and Juan. From the bottom of my heart: thank you.

To Nerve Damage: Everything's gonna be alright. It's gonna be okay.

Lastly, thank you to Kim and all those who came before me. Although this is a Snowflake disease, we are truly in this together.

TABLE OF CONTENTS

Dedication	iii
Abstract	iv
Acknowledgements	v
List of Figures	viii
Introduction	1
Multiple Sclerosis.....	3
My Story.....	6
Methodology	9
Participant Interviews: Findings – Diagnosis, Symptoms, and the Issue of Disability	13
Approach to Research-Creation	17
○ Creating the Performance.....	17
○ Music.....	20
○ Rehearsal	25
Conclusion.....	28
References	32
Appendices	
○ Appendix 1: Recital Program.....	34
○ Appendix 2: Ensemble Photography.....	36
○ Appendix 3: Lethbridge Herald News Article	37
○ Appendix 4: Jeff Beal Program Notes from <i>The Salvage Men</i>	38
○ Appendix 5: Song Lyrics.....	39

LIST OF FIGURES

Figure 1: Jeff Beal interview footage projected	17
Figure 2: Nerve Damage performs “Light of a Clear Blue Morning”	23
Figure 3: JamChor Ensemble rehearses <i>The Salvage Men</i> at the University of Lethbridge	25
Figure 4: Curtain Call	31

INTRODUCTION

On May 13, 2023, I had the privilege of presenting my thesis project entitled *Responding to MS Through Song: A Research-Creation Project*, a work of profound personal significance, at the University of Lethbridge. This project combined live ensemble singing, spoken word, and recorded interviews and songs.

The scope of this thesis project addresses my own experience as a classically trained soprano and extends to community members who are musicians currently living with Multiple Sclerosis. It involved both singers and composers, and the genres of music spanned from Classical to Alternative Rock. In Western classical music, disability has historically been represented as villainous, dissonant, and mad. According to research by Howe and Armstrong, opera is the musical genre with the highest representation of disability, where it is often used in one of two ways: to be comedic, or to instill confusion. They argue that many historical representations of disability support the supercrip discourse, in that characters are given “superhuman” abilities to compensate for disability. Sadly, disability mimicry (a character who has a disability being played by a non-disabled person) is still common to this day.¹ Howe and Armstrong’s online database showcase a multitude of examples of disability represented in concert music, stage music, and popular music.² I intended to showcase music created by those living with MS as something of beauty, advocacy, and importance while allowing each participant to define disability and impairment in a way that felt accurate to them personally.

¹ Bull, Anna, Laudan Nooshin, and Christina Scharff. *Voices for change in the classical music profession: New ideas for tackling inequalities and exclusions*. Oxford University Press, Incorporated, 2023.

² Howe, Blake. “Musical Representation of Disability.” Edited by Charlotte Armstrong. Louisiana, n.d.

Conversations with participants took place over three years, and each participant shared intimate details of their life regarding diagnosis, medication, claiming the word disability, and music. I approached the interviews with eight questions/topics to explore. Each conversation took on a life of its own and blossomed into natural and organic connections between me and the participants. The combination of interviews, live performances, and spoken word resulted in a research-creation project.

Connection, conversation, community, advocacy, and the power of the human voice became the central focus of my work. Living with an invisible disease poses a slew of challenges, as many with MS don't "look" ill. The allowance of expression through both spoken word and song was important. The project became meaningful and moving for both those involved and those who attended the live performance.

In this thesis, you will find sections on Multiple Sclerosis, methodology, research creation, and a detailed account of how this performance piece came to be. It includes true accounts and quotes from people living with Multiple Sclerosis throughout many different seasons of disease progression. These stories are to be read with respect and thoughtfulness. Each participant shared intimate details of their life; it was an honour to be trusted with these precious accounts of the challenges of living with a progressive and incurable autoimmune disease. I have chosen not to include individual names with the quotes because as this work unfolded, their voices came together and told this story as an ensemble.

MULTIPLE SCLEROSIS

“MS...oh great. I have some incurable disease I’m going to die from...”

From initial presenting symptoms to diagnosis, to subsequent disease progression, Multiple Sclerosis shapes the lives of each person living with this disease in different and unique ways. Multiple Sclerosis (MS) is often referred to as “The Snowflake Disease,” meaning that each person has a unique set of symptoms and experiences and that no two MS patients share an identical experience. Each participant in this project described distinct narratives around what life with Multiple Sclerosis is to them, engaging in conversations that were informative, enlightening, and deeply significant. Through a multitude of conversations, I was able to not only learn about each person’s unique journey with the disease but also grasp a better understanding of mine.

MS is a disease of the central nervous system that disrupts the flow of information within the brain and interrupts the connection between the brain and body. The overarching cause of MS is that the myelin sheath which coats the nerves becomes damaged, leaving them exposed, causing them to misfire and create “symptoms” in the body. Sclerosis translates as scars.

Multiple scars. While there is no known cause of Multiple Sclerosis, it is believed that lack of Vitamin D, smoking, Epstein Barr Virus infection, obesity, environmental factors, and genetic factors may all play a role in disease development. MS is more common in females and has a high prevalence in Canada. 90,000 people in Canada live with this disease, and it is hypothesized that the distance from the equator and vitamin D deficiency may play a role in this.

The four types of MS are:

- Clinically Isolated Syndrome (CIS): CIS may or may not progress into MS. To be considered CIS, symptoms must last at least 24 hours, and be caused by inflammation and demyelination in the central nervous system.³
- Relapse-Relapsing Multiple Sclerosis (RRMS) is a type of MS where symptoms come and go. A relapse must last at least 24 hours and have symptoms that worsen. Relapses are followed by a remission, meaning symptoms may lessen or dissipate completely.⁴
- Primary Progressive Multiple Sclerosis (PPMS) is a condition in which the neurological condition worsens steadily in the beginning. A person may have periods of relief, but the body does not go into remission, and the disease continues to worsen over time.
- Secondary Progressive Multiple Sclerosis (SPMS) is like relapse-relapsing multiple sclerosis, in that lesions can be active or in relapse. People with SPMS have higher levels of demyelination. The course of disease progression is aggressive, and it tends to have a more severe level of disability.⁵

MS presents itself through a variety of physical symptoms in the human body, including, but not limited to optic neuritis, balance issues, vertigo, slurred speech, fatigue, bladder and bowel dysfunction, cognitive impairment, sexual dysfunction, MS Hug (a tightening sensation that can

³ “Clinically Isolated Syndrome (CIS).” National Multiple Sclerosis Society. Accessed August 4, 2023. [https://www.nationalmssociety.org/What-is-MS/Types-of-MS/Clinically-Isolated-Syndrome-\(CIS\)](https://www.nationalmssociety.org/What-is-MS/Types-of-MS/Clinically-Isolated-Syndrome-(CIS)).

⁴ “Relapsing-Relapsing Multiple Sclerosis.” JHM, February 21, 2020. <https://www.hopkinsmedicine.org/health/conditions-and-diseases/multiple-sclerosis-ms/relapsing-relapsing-multiple-sclerosis>.

⁵ “Secondary Progressive Multiple Sclerosis (SPMS),” National Multiple Sclerosis Society, accessed August 16, 2023, <https://www.nationalmssociety.org/What-is-MS/Types-of-MS/Secondary-progressive-MS>.

cause chest and rib pain, and a sensation of a band around the ribcage), depression, pain and itching, sensory impairment (numbness/tingling), heat intolerance, falling, issues swallowing, emotional changes, tremors, breathing problems, and weakness. Currently, there is no cure for MS, and disease treatment is managed on a person-to-person basis with a plethora of disease-modifying treatments that include injections, infusions, and oral medications.

Multiple Sclerosis has no cure.

“I won’t die from MS, but I’ll die with it.”

MY STORY

In the summer of 2019, I was diagnosed with Relapse-Remitting Multiple Sclerosis. While driving, I experienced diplopia (double vision), and for nearly a week, I struggled with a sensation that my left eye had gone lazy. I was unable to focus my vision, and it felt as though my eye was floating. During that week, I performed in a concert with my women's choir, and during one of our pieces, I looked out into the audience and saw my father standing beside himself. I realized something was severely wrong and ended up in the emergency room that night, where I had two CT scans. They found nothing. The following week, I was back in the hospital to undergo an emergency MRI, followed by a doctor's appointment where my General Practitioner broke the devastating news to me.

That moment was one of the worst in my entire life. She walked into the room, pushed a box of tissues towards me, and said "...it looks like MS." I do not remember much of what was said after that, as my body went into shock and panic. In that instant, the room had swallowed me whole. I don't know if I heard much of what she said to me, but I vaguely remember her trying to comfort me and assure me that many people with MS live normal lives and that having children would still be a possibility. I walked into the waiting room after the appointment, right past my mother, and straight through the doors of the clinic. When we reached the other side of the doors, I yelled, "***I have MS!***" and collapsed onto the ground in tears. Within two weeks, after meeting with two neurologists, undergoing a series of additional tests, and another MRI, I quickly had a confirmed diagnosis. I had Multiple Sclerosis.

The only person I had known with MS was my aunt, who lived with severe MS, and whose disease progression debilitated her. With extraordinarily little knowledge of the disease, I

was convinced that I would end up in the same condition. I spent a month in bed, almost incapacitated by the fear of what could become of me.

Because I live with Relapse-Remitting MS, my symptoms come and go during flares. Symptoms I live with include optic neuritis, bladder incontinence, muscle spasticity in my back, neck, and legs, loss of ability to walk, tremendous fatigue, significant brain fog, loss of feeling in my hands, tingling in my legs, tremors, balance issues, migraines, Lhermitte's sign (an electric shock sensation that occurs throughout the body caused by tilting of the head), MS hug, difficulty breathing, dysesthesia, and sudden and unpredictable emotional changes. When I reflect on the years I have lived with this disease, enumerating these symptoms feels overwhelming and highly vulnerable. Many of these symptoms often go unspoken.

Through trial and error, my neurologist and I have settled on Teriflunomide as my current course of disease treatment. Teriflunomide is a once-a-day pill that stops T Cells from getting into the brain and spinal cord and is believed to reduce the number of relapses by 31% and slow the worsening of impairment by 30%. Side effects of this drug have been hair loss, gastrointestinal problems, and loss of toenails. Other medications I take are Oxybutynin for bladder control, and Vitamin D due to deficiency.

During this first documented relapse, I was scheduled to perform a wedding gig and was unable to find anyone to replace me with such short notice. I performed the gig with double vision, and as I watched the bride walk down the aisle next to herself, I realized something important: While singing, I felt better.

I had never considered that there may be other musicians living with this disease. I began searching for singers with MS and was elated to learn I was not alone. I first discovered MS

Advocate, Britt Quiroz (known as A Hot MS⁶), singing her original song, *Where Were You*, which was written about her diagnosis. I then discovered that Art Alexakis from the American Rock band, Everclear, had been diagnosed with the disease in 2016. I learned that Emmy Award Winning Composer Jeff Beal lives with the disease, and had composed a choral song cycle, *The Salvage Men*, during the time of his diagnosis. Members of my personal MS community began reaching out to me. Kathryn Ferguson approached me with a song she had written about MS, and I learned the following autumn that two members of my women's choir lived with MS. We became fast friends. I suddenly felt less alone and inclined to create something out of the lamentable diagnosis I was dealt. As a soprano and an artist, I have always expressed myself through song, and I knew that I could connect with these like-minded people. This was the beginning of my thesis project.

⁶ "A Hot MS," A Hot MS, accessed October 12, 2023, <https://ahotms.com/>.

METHODOLOGY

When I began my research, I had a desire to study the connection between singing and Multiple Sclerosis with a focus on feelings of wellness during the act of singing. Initially, I had planned for this project to have a scientific disposition. As I began my research, the thesis went through a substantial transformation and flourished into a creative performance utilizing phenomenological and qualitative approaches. I began communicating with my participants and reflecting on what I would want to experience as someone living with the disease. I turned to the idea of research-creation. Stévanice and Lacasse define research-creation as “an *approach* applied to an individual or multiple-agent *project* combining research *methods* and creative *practices* within a dynamic frame of casual *interaction* and leading both scholars and artefactual *productions*.”⁷ It was when I began to understand research-creation that I felt that my voice as an artist and as a member of the MS community could be used in a powerful and impactful way. The conversations with participants were my research, and their stories created our performance.

I engaged in the practice of body-oriented musicology, commonly referred to as ‘performance studies’, which uses the performer’s body as the main source of information.⁸ As my body was ever-changing and I experienced different symptoms daily, I found myself needing to adapt my body and instrument usage. The process of retraining my body acted as a reflexive method of study and helped gather insight into the experience of living and singing with MS. This body-oriented research influenced my interactions with each participant, and the conversation topics that arose.

⁷ Stévanice, Sophie, and Serge Lacasse. *Research-Creation in Music and the Arts*. New York: Routledge, 2018.

⁸ Alejandro Alberto, Tellez Vargas. (2018). *Disability and Music Performance*. Routledge.

This thesis project included six interviewees who are singers and/or composers living with Multiple Sclerosis, a choral ensemble of thirteen members (including myself), three of whom live with MS, and an audio/video engineer. The participants were personally selected. Britt Quiroz and Kathryn Ferguson were part of my online Instagram circle, and I contacted them about this project through direct message. Randi Martens, Tiffany Badiuk, and I were members of a women's chorus and discussed the project in person after discovering we all lived with MS. To contact Jeff Beal and Art Alexakis, I worked with their management to set up interviews and permission to use their music. Initial conversations with participants were used to gauge the interest of fellow "MSers," and once I received a warm reception to my idea, I began structuring this project. Human Ethics requirements were accepted by the University. Each participant was sent a formal invitation and permission request for their interview footage to be used in a live performance piece, satisfying the research ethics requirements. All interviews took place via Zoom.

I approached each interview with a set of eight topics. These interviews were far more than just medicalized data about the disease. The musicians were invited to share as much or as little about their lived experience that they felt comfortable with. Each participant shared the immense difficulties of living with MS, balanced with the lessons that they had learned in gratitude, light, and positivity.

The following questions and conversation topics were offered to each participant:

Diagnosis

1. How were you diagnosed with MS/What is the story of your diagnosis?
 - a. Once you were diagnosed with MS, did your body make more sense to you?
 - b. Have you experienced symptoms for a long time before your official diagnosis?
2. How did you feel after your diagnosis/how did you handle the news?

- a. Did you know anything about MS before your diagnosis?

Symptoms

1. What symptoms do you or have you experienced with your MS, and how do you treat/tolerate/ manage them?

Disease Modifying Treatments

1. Are you on or have you been on any disease-modifying treatments? If so, are you comfortable discussing it? If not, how did you make the decision not to use medication?

Disability

1. Based on my research of disability representation in music, I feel that it is important for proper first-person representation and the need to allow those living with a disability to define the word disabled. Do you consider yourself disabled? Why or why not?
 - a. How do you define the word disability about your own disease?

Singing/Music

1. Tell me about your life as a singer.
 - a. When did you start singing?
 - b. What musical styles do you sing?
 - c. How has singing impacted you as a person?
 - i. For those of you who compose music, how has MS influenced your compositions?

The initial question served as the launch of a lengthy conversation with each person. Most participants are living with Relapse-Remitting Multiple Sclerosis and one with Primary Progressive Multiple Sclerosis. In discussing their diagnosis stories, I discovered that while many of us have similarities in our disease experiences, no two stories were the same. These stories became the central narrative of my live performance. Both the songs shared by Art

Alexakis and Britt Quiroz, as well as the multi-movement choral work by Jeff Beal center around the moment of MS diagnosis. The strength and variety of these feelings, and the impact on the musicians became the heart of my work.

PARTICIPANT INTERVIEWS: FINDINGS – DIAGNOSIS, SYMPTOMS, AND THE ISSUE OF DISABILITY

The consensus was that living with Multiple Sclerosis is unquestionably difficult. Each participant was required to relearn things about themselves and their bodies as they faced new and ever-changing symptoms. Each person discussed the challenge of moving from grief and denial to acceptance and understanding as they learned to live with an incurable autoimmune disease.

“My MRI lit up like a Christmas Tree.”

Each person’s diagnosis was unique. For some, it was a quick process that involved one MRI, and for others, it took years and multiple tests to discover. MS is typically diagnosed through a series of MRIs that scan the brain and identify any inflammation within. These detect the location of scarring in both the brain and the spinal cord. Many participants were initially worried that they would receive a diagnosis of a brain tumour, and were relieved that it was “only” MS.

“My doctor looked at me and said...well...good news...you don’t have a brain tumour.”

The symptoms that the participants shared with me were double vision, bowel incontinence, bladder incontinence, seizures and epilepsy caused by disease progression, drop-foot (difficulty lifting the foot which can cause it to drag), Lhermitte’s sign, muscle spasticity, rage, severe mood swings, heat sensitivity, numb extremities, fatigue, migraines, neuropathy, balance issues, leg shakes, cognitive issues, tingling, vertigo, insomnia, muscle weakness, vibrations in the body, transient muscle and joint pain unrelated to physical activity, and hot flashes.

“If you want to feel like what MS feels like, go get drunk and tie your feet together.”

When discussing disability, I came to understand that the word should not be defined as a blanket term. MS Canada considers Multiple Sclerosis an “episodic disability,” meaning that the duration and severity of illness and disability vary.⁹ Many participants did not identify with the word disability at all. My project aimed to challenge how disability is so often discussed and researched, by adding my voice as a “disabled” researcher. I use quotation marks when referring to myself, as I am still learning about my life with Multiple Sclerosis and have not yet defined the word regarding my own lived experience. My disease progression has been slow over the course of the last three years, thus leading me to relate more to the word impaired. Joseph Straus defines impairment as an underlying biological and medical condition, and disability as the social and cultural construct that we live in that creates barriers for many.¹⁰ Over the course of my life with MS, I have paid close attention to the societal constructs that create disability. If all humans were given individual constructs to suit their lived experiences, and if the focus was shifted from the medicalization of disability, would disability itself exist? This idea was discussed with each participant, and I found that though they are deemed medically impaired, some did not identify with the word “disability” at all. It was imperative to me as a researcher to approach disability in an ethical manner, allowing participants to create unique definitions based on their experience, and claim the word if they saw fit.

⁹ “Canada Disability Benefit Legislation Important for Canadians Affected by MS to Make Ends Meet.” MS Canada. <https://mscanada.ca>.

¹⁰ Joseph N. Straus, "Normalizing the Abnormal: Disability in Music and Music Theory," *Journal of the American Musicological Society* 59 (2006): 113-184.

Disabled researchers, Kerschbaum and Price, suggest that disability should be defined in terms of how people develop knowledge about the world with which they interact. They stress a heavy importance on the word *disability*, and the need for disabled people to define this word. It should not be defined by able bodied people who are not hindered by societal constructs. They discuss the need for equitable practices in qualitative interviews and research methods. They suggest that a disabled interviewer must place importance on their own needs, as opposed to solely the needs of the interviewee. Centering and respecting disability within the interviewer is crucial. Disabled researchers must remain self-aware of such issues as impairments such as fatigue, brain fog, and panic.¹¹ I was careful to respect my own body during the process of this thesis creation.

In my interviews, when the topic turned to music it was unanimous that music functioned as wellness and healing for each person. It was obvious to me that each of these people had a profound and inherent need to make music. When participants discussed the specifics of their artistic journey as a musician with MS, it changed the tone of the discussion. I was speaking to artists who were willing to share the depths of their soul through their musical creations. From church choirs to musical theatre, to rock, pop, jazz, folk, and opera, the participants all shared memories and encounters from their lives as musicians.

As Boiko, Ivanchuk, Gunchenko, and Batysheva argue, music can be used to regulate the psychosomatic and psycho-emotional processes in the human body. Music's sedative function

¹¹ Kerschbaum, S. L., & Price, M. (2017). Centering Disability in Qualitative Interviewing. *Research in the Teaching of English*, 52(1), 98-107.

can release both physical and emotional tension and create strength.¹² The idea of using music as relaxation and catharsis was a common theme between my interview participants, and many discussed out-of-body musical experiences that lead to sensations of wellness, healing, and calm.

¹² Boiko, E. A., Ivanchuk, E. V., Gunchenko, M. M., & Batysheva, T. T. (2017). The Potential of Music Therapy in Neurology Using Multiple Sclerosis as an Example. *Neuroscience and Behavioral Physiology*, 47(5), 570–572.

APPROACH TO RESEARCH-CREATION: CREATING THE PERFORMANCE

This thesis performance was designed to include live choral singing, small group performances, and an extensive video montage of participant interviews, as well as my own diagnosis monologue. I organized and rehearsed the choral and trio ensembles for the live performance, conducted all interviews, and oversaw technical elements.

I worked with audio/video engineer, Chris Bernhardt, whose strong skills enhanced the calibre of my staged performance. Chris worked with the back-of-house stage manager who communicated in real-time during the dress rehearsal and performance to ensure entrances and lighting changes happened smoothly.

To prepare the video elements, Chris and I viewed video interviews, created time stamps, and compressed over six hours of footage into brief selected segments that were then interspersed into the live element of the concert.



Figure 1: Jeff Beal interview footage projected. Photograph by Ian Martens

To maintain the dignity and trust of my participants, I conducted interviews on my own without expert technical intervention. Once the interviews were complete, I reviewed the footage and selected potential moments to incorporate into my final performance. I sent time stamps to Chris, who spliced and compiled the footage. Reviewing these interviews was difficult. Participants shared some of the worst moments of their lives with me. The clips incorporated in the live performance were organized based on themes presented in the music. Jeff Beal's discussion of *The Salvage Men* became an important lead-in to the three selections performed by the choral ensemble.

For the first half of the performance the choir sat motionless on the darkened stage as interview clips played on the large projection screen in the recital hall. Stage cues were carefully decided and rehearsed to provide seamless transitions between sitting, moving to music stands, and beginning to sing.

Once the live and recorded elements were carefully placed in order, I ran technical rehearsals and invited the ensemble to view the footage. I planned lighting cues, discussed staging, chair placement, position of the singers, entrances and exits, and the final curtain call.

The most challenging part of the entire performance was the moment I sat alone on the stage under a spotlight, making direct eye contact with my audience while the audio played behind me of my own journey with MS. I sat bathed in the sound of my own experience. Much of this discussion had never been uttered aloud. I would not have been able to communicate those words in person, so the ability to have my audio professionally recorded allowed me to share aspects of my story that were highly vulnerable and displayed an uncomfortable part of my reality. I felt a sense of achievement when I was able to sit in stillness and remain calm. As this moment played in the first dress rehearsal, I realized that this was the first time I had shown sincere vulnerability and was hit with a wave of emotion. I ran to the hallway to weep. I felt that

in sharing my story, I released a part of me that had been weighing on me emotionally. Being able to tell my story with no opportunity for pushback or disbelief was freeing, heavy, and much needed. In that moment, I felt even more pride in the project, knowing that along with my interview participants, my story was shared as well.

MUSIC

“When you hear a human singing, it’s like a love language in a way.”

A carefully curated collection of work that represented the voices of MS and my own interpretation of disease trajectory was performed in this thesis performance. Each composition was selected before putting the final work together, but the order did not become clear to me until I experienced many meaningful conversations with my ensemble. I intended for the musical pilgrimage to mirror that of being diagnosed and living with Multiple Sclerosis. I was deliberate in choosing musical selections that would force the audience to feel uncomfortable at first and resolve with a sense of acceptance and understanding.

On the night Jeff Beal was diagnosed with MS, he sat in his home and listened to Eric Whitacre’s Cloudburst record. Beal’s career has focused on instrumental film music. Eric Whitacre is the vocal composer whose ensemble recorded *The Salvage Men*. I connected with Beal deeply as he discussed his love of choral music and the power of the human voice. He expressed that the first time he and his wife listened to *The Salvage Men* live, they both began to weep. Beal discussed with me the healing power of music in a tumultuous time.

During my conversation with Beal, I learned that at the first rehearsal and first public performance of *The Salvage Men* with Eric Whitacre, the singers were hooked up to sensors that were monitoring the bodily changes experienced during singing. There was a synchronicity to what he was experiencing in his own life at the time, and I was eager to further research the effects that this music had on its singers. During our conversations, Beal placed great interest on the scientific studies involving the impact on the body while singing.

“How different is my world going to be?”

In his program notes, Beal writes:

...at the very same time we were working on this project, I found myself in the midst of an unexpected health crisis, which eventually lead to a diagnosis of Multiple Sclerosis. Wilde’s *De Profundis* came at the beginning of a journey in learning how to live gracefully with an uninvited guest. Thankfully, my disease remains mostly in remission, but I deal with neuropathic pain and other issues that those living with a chronic illness intimately understand. Music is more than a vocation, it is an integral part of my daily life, as composing, listening to and performing music lessens pain and energizes me.

Beal’s program notes spoke to my own connection with singing, and the idea that the act of singing provides a pathway to healing, wellness, and pain relief.¹³ In my conversations with Beal, he expressed an emphasis on text, and the need to interpret the poetry of each piece.

I selected to have my choral ensemble perform three outstanding movements from Beal’s multi-movement work, *The Salvage Men*. Although the ensemble learned Beal’s work in its entirety, the choir responded strongly to the movements with poetry by Kay Ryan and Oscar Wilde. The three movements selected were “A Very Long Moment,” “Spiderweb,” and “Virga.”

The movements from *The Salvage Men* were challenging to learn, as Beal’s complex lines and unsuspecting compositional turns were new to the ensemble. Things that became important in the group were blending, visual communication between singers, and trust. As there was often only one voice to a part, it was essential that each ensemble member learned the music on their own time, so we could focus on musical nuances when we came together.

¹³ See: Jeff Beal, *The Salvage Men*, (Los Angeles: St Rose Music Publishing, 2015) Beal’s extensive introduction to this choral work helps the reader place this work in context concerning diagnosis with Multiple Sclerosis.

The first piece in this work, “A Very Long Moment,” with poetry by Oscar Wilde, is a meditation on suffering. This disjunct and challenging vocal work moves singers to the edge of their musical technique and requires extreme vocal independence. Beal’s unusual melodies and intricate patterns lend themselves to the idea of confusion and disarray at a time of turmoil.

The movement titled “Spiderweb” lends itself to the idea of the supercrip¹⁴ narrative, offering varied perspectives on the spiderweb. When discussing Spiderweb, Beal emphasized that from the outside looking in, one views a spiderweb as a majestic creation, but to the spider, it is arduous work. He compared this to people viewing each other’s lives through rose coloured glasses, when in fact each person may have a personal struggle that cannot be seen with the naked eye. As MS is an invisible illness, I found the poetry moving and relatable. Many people living with disabilities are placed on a pedestal for performing everyday tasks when viewed by the non-disabled community.

“Virga,” the third piece, has moments of traditional tonality and a sensation of repose. This was the only point in the performance where I functioned as a vocal soloist. The high soprano line soared above the ensemble and allowed me to transcend the difficulty of the topic. Beal’s works, intertwined with interview footage, made up the first half of the performance.

MS activist, Britt Quiroz and Rock headliner Art Alexakis’s music was presented in the second half of the performance. Each of their music videos were projected on the large screen at the back of the Recital Hall stage. Quiroz’s powerful lyrics expressed the overwhelming emotions surrounding her diagnosis. The song, titled “Where Were You,” could be considered an MS anthem in that it emphasizes the power of healing, belief, and perseverance. The music and

¹⁴ “Re-evaluating the Supercrip - Sami Schalk.” samischalk.com. Accessed October 13, 2023.

lyrics were written by Quiroz and her collaborative partner and mother, Kristen Spath. Art Alexakis, from the American rock band Everclear, graciously allowed me to include his music video for the song, “Hot Water Test,” from his 2019 solo album *Sun Songs*, which recounts the day of his diagnosis. In this video, Alexakis invited members of the MS community who displayed great vulnerability as they lip-synced his lyrics. The song is titled after a historic (and barbaric) diagnosis technique. People suspected to be living with the disease were placed in baths of extremely hot water, and if symptoms worsened, they received diagnosis. The music in the second half of the performance demonstrated resilience and acceptance. It concluded with a performance by Nerve Damage, a vocal trio consisting of members Tiffany Badiuk, Randi Martens, and myself. We performed the Wailin’ Jennys arrangement of “Light of a Clear Blue Morning,” by Dolly Parton. This piece performed by Nerve Damage was selected by Randi Martens. In discussing which song we wanted to share with our audience, we decided that the words of this piece resonated deeply with each of us, as they too told of a journey from darkness to light.



Figure 2: Nerve Damage (Tiffany Badiuk, Jaimee Jarvie, and Randi Martens) performs “Light of a Clear Blue Morning.” Photograph by Ian Martens

The musical selections in my performance were influenced by conversations with each participant. During the preliminary stages of this project, *The Salvage Men* was intended to be the sole artistic element within the concert. As I met with each participant over the course of three years, further musical elements were added to this thesis project. These song selections happened naturally with each of them being chosen by or performed by participants. The careful sequencing of the repertoire for this performance was then established. As people living with MS often refer to it as their “journey,” I intended for the audience to embark on a journey of their own as the music moved from jarring and confusing, to melodic and relieving – mirroring the feelings that I personally encountered in the time since receiving my own diagnosis.

REHEARSAL

The choral ensemble that performed in my thesis presentation named itself *JamChor*. The ensemble met one to two times a month from September 2022 until May 2023. The group consisted of community members, University of Lethbridge undergraduate students, and alumni. My ensemble included guitar and piano majors, and singers with and without formal vocal training. Although musicianship is a treasured and necessary aspect of choral music-making, my objective was to create a cohesive vocal group that could sing together, nurture connections and relationships, and engage in meaningful conversation. The first thirty minutes of each rehearsal provided the ensemble with a safe and inclusive environment to explore the difficult topics of this project.



Figure 3: JamChor Ensemble rehearses *The Salvage Men* at the University of Lethbridge

In his book, *Broken Beauty*, music theorist Joseph N. Straus deconstructs the idea that music must be “perfect,” and suggests that it is imperative that we move away from the idea of correcting music. He aims to allow for disability to claim its own voice and place in music in a

positive and empowering light.¹⁵ In working with singers of varied skill levels, I was forced to re-evaluate the leadership role that I took in the ensemble. A highly sensitive approach was necessary as I uncovered the needs of each individual member. Some of the needs of the ensemble included singing seated, allowing for more time for stage movement, taking frequent breaks within the rehearsals, accepting tardiness due to non-accessible routes and lack of handicapped parking, and allowing for a safe space for emotions within rehearsals. Freedom of choice was encouraged within the performance dress code, allowing for personal expression and accommodation of comfortable choices.

As many of the ensemble members knew nothing about MS, the three members living with the disease provided an honest glimpse into the lives of those with MS, discussing symptoms, disease progression, and unfortunate happenings in our lives. Topics such as bladder and bowel incontinence appeared to make the group the most uncomfortable. We continued to talk about our experiences, sparing no embarrassing detail. Through these challenging conversations, the ensemble learned that they were able to ask questions, provide support, and remove difficult barriers. It was during one of our hard conversations that I identified a possible trajectory for the musical selections. I intended for the musical pilgrimage to mirror my experience with diagnosis and living with Multiple Sclerosis: moving from devastating confusion to understanding, to acceptance.

During rehearsals, many challenges arose. As an ensemble, we navigated illness, interpersonal relationships, blending, tuning issues, and coordinating schedules of thirteen individuals. I was careful to create an inclusive rehearsal and performance space that addressed

¹⁵ Straus, J.N. (2018). *Broken Beauty: Musical Modernism and the Representation of Disability*. Oxford University Press.

the traditional constraints forced on disabled bodies. Howe discusses the societal construct of what it means to be able-bodied and the importance of creating inclusive performance structure. He emphasizes the need to abandon the idea that disability is how the body works, but rather the way it is forced to interact with the environment in which it lives.¹⁶

As someone who lives with Multiple Sclerosis, I encountered personal challenges during rehearsals. Fatigue, neuropathic pain, sensory overload, and mood swings occurred. I began to understand the need to protect disabled researchers and allow for deviations from the “norm.” I was forced to listen to my body and create a distinct way of conducting and participating in rehearsals. This included taking many breaks, conducting all rehearsals seated, dressing in non-constricting clothing, assessing body temperature, and constantly addressing stress levels within myself. As someone with symptoms that exacerbate suddenly when stress levels increase, there were moments in rehearsal where things were halted to maintain a level of calm.

I took on multiple roles in this project. I functioned as conductor and musical director for the vocal ensemble as well as a soprano within both vocal groups. It was difficult to relinquish control, as the ensemble was expected to learn this challenging music on their own. Functioning as the organizational project manager for this thesis required a different skillset than being a singer. I valued good collaboration, prioritized, and maintained organized professional rehearsals, and managed challenging logistical issues. I felt immense pressure in presenting a highly personal thesis project to friends, family, colleagues, and community.

¹⁶ Howe, B., Jensen-Moulton, S., Lerner, N. W., Straus, J. N., & ebrary, I. (2016;2015;). *The Oxford Handbook of Music and Disability Studies*. Oxford University Press.

CONCLUSION

The primary objective of this project was to educate the audience about Multiple Sclerosis, its progression, and the various degrees of impairment it can cause through the lens of vocal music composed and performed by individuals living with MS. This approach was designed to offer a more authentic representation of MS, as it is often misunderstood or misrepresented in medicalized terms. Straus argues that the medicalization of disability creates the idea that disability is the “deviance from the norm,” and that disability is often considered a “burden or tragedy.”¹⁷

One of the key insights from the project was the realization that disability can be defined in many ways, and it is crucial that these definitions are shaped by those who experience it. This was evident in a conversation with a participant who initially did not know that I had MS. Upon sharing my personal story, their demeanour changed instantly from guarded to warm and receptive. This experience underscored the importance of non-medicalized narratives in understanding disability, as they can offer a more nuanced and relatable perspective.

The project also highlighted the relief participants felt when they were not being "studied," but rather listened to and believed. This experience was a stark contrast to the common perception that people with disabilities are often assessed in a medicalized way. The project aimed to challenge this perception and provide a platform for individuals living with MS to share their experiences and perspectives without being medicalized. Historically in music studies, disability has been defined by non-disabled researchers, who create their own narratives of how the disabled express themselves through music. Removing interpretation of how disabled

¹⁷ Straus, J. (2006). Normalizing the Abnormal: Disability in Music and Music Theory. *Journal of the American Musicological Society*, 59(1), 113-184.

people feel, think, or hear music is imperative to honouring disabled performers and musicians.¹⁸ Reclaiming the word disability was a strong theme throughout my research.

In essence, the project sought to create a space where individuals living with MS could share their stories and experiences, providing a more accurate and relatable portrayal of the disease. This was achieved by focusing on the music composed and performed by these individuals, offering a non-medicalized perspective on MS. By providing a vehicle for authentic narratives and experience, this project served as a platform for artistry. It allowed those with MS to respond directly to their lived experiences, voicing their own truths through spoken word and song.

The audience's positive response and engagement was overwhelming, with members of the MS community expressing gratitude for an honest, raw, yet uplifting depiction of the disease. This representation provided insight and knowledge of disability to those who were previously unaware of it. Musicians, who have had extensive careers as singers and conductors, were moved by the concept of complete inclusivity within an ensemble and expressed a desire to revolutionize the way they manage ensembles going forward. My own family members were taken aback by the revelation of the daily challenges I face, underscoring the importance of such open discussions in fostering understanding and empathy. Although disability research within music is starting to gain traction, I feel that there is still work to be done within the field. In many ensembles that I have been a part of, I have noticed a lack of understanding for personal needs and holding onto traditional ways of rehearsing and performing. There needs to be a universal shift towards accommodating performers, and consideration for the obstacles that

¹⁸ Howe, Blake, Jensen-Moulton, Stephanie, Lerner, Neil, and Straus, Joseph, eds. *The Oxford Handbook of Music and Disability Studies*. Oxford: Oxford University Press, 2015. Accessed November 29, 2020. ProQuest Ebook Central.

create disability within a group. Bassler discusses the “cure narrative,” used in the medical model, and that the medicalization of disability aims to “cure” the disabled body, rather than examine the environment in which it lives.¹⁹

The Lethbridge Herald's coverage of my performance and the associated research garnered attention within the community, fostering an increased level of interest. By publicizing this endeavour, the newspaper was instrumental in attracting a more diverse audience, thereby amplifying the event's reach. Moreover, the exposure generated by the Lethbridge Herald extended beyond the immediate community, reaching members of the Multiple Sclerosis community who would likely have remained unaware of the project otherwise.

The greatest takeaway from this thesis was the eye-opening experience of exploring the need for inclusivity within ensembles, music programs, and conservatories. After teaching privately and publicly as a music teacher in Mexico City, Telez Vargas wrote extensively on the topic of disability within music performance. The school in which he taught had an exceptionally inclusive music program, and after working in these surroundings, he began to challenge the idea of discriminatory practices in conservatories, orchestras, and competitions. His book touches on the topic of disabled musicians' challenges when striving for professional music careers.²⁰ There is an intense need to deconstruct negative language and discourse surrounding disability and examine social constructs within music that cause one to be more disabled than a non-disabled body.

As a classically trained soprano, I have experienced the competition and exclusivity in

¹⁹ “*But You Don’t Look Sick*”: *Dismodernism, Disability Studies and Music Therapy on Invisible Illness and the Unstable Body* – Samantha Bassler
– <https://doi.org/10.15845/voices.v13i3.802>

²⁰ Alejandro Alberto, Tellez Vargas. (2018). *Disability and Music Performance*. Routledge.

ensembles first hand, and as I continue researching disability in music, I aim to challenge this.

Sadly, it was not until I was diagnosed with Multiple Sclerosis that I began to understand the constructs that limit people in musical settings. Something that seems small to a non-disabled person can have an immense toll on someone living with a disability. Standing throughout an entire concert is but one example of the traditional practices that could be challenged. I believe that disabled researchers must be taken seriously, as they are the ones who experience the burdens that the non-disabled cannot understand.

I believe there must be a universal shift in the ways of approaching music ensemble activity, both in academic and community settings. Guidelines do not exist on how to ethically approach matters of disability and/or impairment within music ensembles. Further examination of this topic seems necessary, timely, and overlooked.

“You don’t get it until you get it.”



Figure 4: Curtain Call – Photograph by Ian Martens

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APPENDIX 1: RECITAL PROGRAM

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Isaac Risling – Rehearsal Pianist
Tanner Lapointe – Rehearsal Assistant
Dr. Janet Youngdahl - Supervisor
Dr. Monique Giroux – Committee Member
Mia van Leeuwen – Committee Member
Kim Arkley - Forever in my heart

The University of Lethbridge Faculty of Fine Arts
Department of Music Presents



From the studio of Dr. Janet Youngdahl

Responding to MS Through Song: A Research-Creation Project

Jaimee Jarvie

Soprano/Researcher/M.Mus Candidate

Saturday, May 13, 2023, 7:30 PM
University of Lethbridge Recital Hall



Art Alexakis
Singer and Lead Guitarist of Everclear
Grammy Nominated Rock Musician
Three platinum albums - *Sparkle & Fade*, *So Much for the Afterglow*, and *Songs from an American Movie Vol. One: Learning How to Smile*.
Diagnosed with MS in 2016



Jeff Beal
Film and Television Composer
Jazz Instrumentalist
19 Primetime Emmy Nominations
Five-time Emmy Award Winner - 2003, 2007, 2008, 2015, 2017
jeffbeal.com
Diagnosed with MS in 2007



Britt Quiroz
MS Advocate – A Hot MS
Host of the Podcast “All the Odds with A Hot MS”
Writer, Speaker, Artist, Disability Advocate, Model and Content Creator for the Multiple Sclerosis & Chronic Illness Community.
Diagnosed with MS in 2019

by Oscar Wilde – from *Die Profundis and Other Writings*

Suffering is one very long moment. We cannot divide it by seasons. We can only record its moods, and chronicle their return. With us time itself does not progress. It revolves. It seems to circle round one centre of pain.

Spiderweb
by Kay Ryan

From other angles the fibers look fragile, but not from the spider's, always hauling coarse ropes, hitching lines to the best posts possible. It's heavy work everywhere, fighting sag, winching up give. It isn't ever delicate to live.

Virga
by Kay Ryan

There are bands in the sky where what happens matches prayers. Clouds blacken and inky rain hatches the air like angled writing, the very transcription of a pure command, steady from a steady hand. Drought put to rout, visible a mile above for miles about.



In 2019, I was diagnosed with Relapse-Remitting Multiple Sclerosis. As a singer this was terrifying. With MS, you don't know what your body is going to do from day to day, and it occurred to me that one day I may not be able to sing anymore. My perspective on life changed, and thus began the creation of this project.

Over the course of the last three years, I have had the utmost honour of speaking with singers and musicians around the globe living with MS. We discussed a multitude of topics, from disease modifying drugs, to diagnosis stories, to whether they identify as disabled or not. The conversations came to life when we talked about music. Singing has acted as a form of therapy for all of us.

This project features interview footage from Art Alexakis of the band Everclear, Emmy Award Winning Composer Jeff Beal, MS Advocates Britt Quiroz (A Hot MS), and Kathryn Ferguson, and my dear friends Randi Martens and Tiffany Badiuk.

My ensemble *JamChor* consists of 13 musicians (some living with MS) and is a hand selected ensemble of singers that I've had the pleasure of working with in different capacities over the last three years.

The trio you will hear at the end of the show is *Nerve Damage*. The name began as a joke, but the three of us could never find anything else that captured the essence of our humour. We're just three gals living with MS that love to sing.

The music you will hear was carefully selected. We begin with Eric Whitacre's *Cloudburst*, which is a piece that Jeff Beal listened to on the night of his diagnosis. The three selections from Beal's choral work *The Salvage Men*, were composed during his own diagnosis. *Where Were You?*, written by Britt Quiroz, is reflection on the day she was diagnosed. *The Hot Water Test*, by Art Alexakis, features people living with MS, and tells the story of overcoming the fear of this disease. *Light of a Clear Blue Morning*, by Dolly Parton was selected by Nerve Damage, as the lyrics reflect hope, perseverance, and finding the light in the face of adversity.



Randi Martens
Choral Singer
Ventus Women's Choir University of Lethbridge Singers
JamChor
Nerve Damage Trio
Diagnosed with MS in 2006



Tiffany Badiuk
Choral Singer
Past member of the Anne Campbell Jr. Choir, and Vox Musica
Ventus Women's Choir
JamChor
Nerve Damage Trio
Diagnosed with MS in 2008



Kathryn Ferguson
Actor
Teacher
MS Advocate and Ambassador
Choral Singer
2019 MS Society Top Fundraiser recipient
Diagnosed with MS in 2017

Nerve Damage



Jaimee Jarvie - Soprano
Randi Martens - Soprano
Tiffany Badiuk - Alto

JamChor



Soprano: Jaimee Jarvie, Noelle Kuntz
Alto: Julena Andrew, Tiffany Badiuk, Rosie Crisp, Randi Martens
Tenor: Dacs Ambrose, Franz Faeldo, Bryce Johnston, Isaac Risling
Bass: Carson Froehlich, Adam Kennedy, Tanner Lapointe

Program Order

Please hold your applause until the end of each half

The Salvage Men – Jeff Beal – Performed by JamChor

- I. **A Very Long Moment** – Poetry by Oscar Wilde
- II. **Spiderweb** – Poetry by Kay Ryan
- III. **Virga** – Poetry by Kay Ryan

Intermission

Where Were You? – Britt Quiroz

The Hot Water Test – Art Alexakis

Light of a Clear Blue Morning – Dolly Parton, arr. The Wailin' Jennys – Performed by Nerve Damage

APPENDIX 2: ENSEMBLE PHOTOGRAPHY



APPENDIX 4: JEFF BEAL PROGRAM NOTES FROM *THE SALVAGE MEN*

Notes

Oscar Wilde was sentenced to two years of hard labour at Reading Gaol prison in London, after he was prosecuted and convicted for his love affair with another man. This imprisonment had a devastating effect on Wilde's health and spirit. Wilde died in Paris soon after his release from prison, at the age of 46. *De Profundis* (from the depths) is the poignant letter Wilde wrote from prison, reflecting on the horrors of imprisonment, the nature of human suffering and our chosen response. Wilde's choice was to write.

I was first exposed to this deeply moving letter in 2007, while scoring the documentary *Wilde Salome* for director Al Pacino. Several scenes in the film featured his reading from *De Profundis* and portrayal of Wilde's arrest and last days in Paris. At the very same time we were working on this project, I found myself in the midst of an unexpected health crisis, which eventually lead to a diagnosis of Multiple Sclerosis. Wilde's *De Profundis* came at the beginning of a journey in learning how to live gracefully with an uninvited guest. Thankfully, my disease remains mostly in remission, but I deal with neuropathic pain and other issues that those living with a chronic illness intimately understand. Music is more than a vocation, it is an integral part of my daily life, as composing, listening to and performing music lessens pain and energizes me.

The lyrical beauty of *De Profundis* gave me the original impetus for a choral work. His words provided an entry point into this meditation on suffering and catharsis. However, it was in the poetry of Kay Ryan I found a wholly fresh, contemporary view on the themes of transformation and our chosen response to pain. Ryan's writing style is very different from Wilde's. She does not use the personal voice, and avoids confession. Her poetry has a circular quality to it. A revelatory line at the end of Ryan's poetry often invites the listener to reflect back to the beginning, once a poem is finished. Ryan often will recite her brief poems twice in readings, to allow listeners this understanding. I find her poetry to have a deeply musical quality, not unlike the da capo aria.

I began working on the choral settings while visiting Paris during the spring of 2014. Aimlessly wandering the streets of the Left Bank with my wife, we came across an entry to a building that looked familiar. I soon realized we had stopped in front of L'Hotel--the hotel where Wilde had spent his final days on earth. I had just begun setting Wilde's text to music, and here we were, most unexpectedly, at his doorstep. These patterns in music, poetry and life might be viewed as signposts, encouragements, divine coincidences. It is our choice which makes them so.

Jeff Beal

Plaque honoring Oscar Wilde, L'Hotel Paris spring 2014



APPENDIX 5: SONG LYRICS

Cloudburst – Eric Whitacre

La lluvia...
Ojos de agua de sombra
Ojos de agua de pozo
Ojos de agua de sueño
Soles azules, verdes remolinos
Picos de luz que abren astros
Como granadas
Dime, tierra quemada, no hay agua?
Hay sólo sangre, sólo hay polvo
Sólo pisadas de pies desnudos sobre la
espina?
La lluvia despierta...
Hay que dormir con los ojos abiertos
Hay que soñar con las manos
Soñemos sueños activos de río buscando su
cauce
Sueños de sol soñando sus mundos
Hay que soñar en voz alta
Hay que cantar hasta que el canto eche
Raíces, tronco, ramas, pájaros, astros
Hay que desenterrar la palabra perdida
Recordar lo que dicen la sangre y la marea
Le tierra y el cuerpo
Volver al punto de partida...

The rain ...
Eyes of shadow-water
eyes of well-water
eyes of dream-water.
Blue suns, green whirlwinds,
bird beaks of light pecking open
pomegranate stars.
But tell me, burnt earth,
is there no water?
Only blood, only dust,
only naked footsteps on the thorns?

The rain awakens ...
We must sleep with open eyes,
(...) we must dream aloud,
we must sing till the song
puts forth roots,
trunk, branches, birds, stars,
we must find the lost word,
and remember
what the blood, the tides,
the earth, and the body say,
and return to the point of departure...

The Salvage Men

A Very Long Moment

by Oscar Wilde – from *Die Profundis and Other Writings*

Suffering is one very long moment. We cannot divide it by seasons. We can only record its moods, and chronicle their return. With us time itself does not progress. It revolves. It seems to circle round one centre of pain.

Spiderweb

by Kay Ryan

From other
angles the
fibers look
fragile, but
not from the
spider's, always
hauling coarse
ropes, hitching
lines to the
best posts
possible. It's
heavy work
everyplace,
fighting sag,
winching up
give. It
isn't ever
delicate
to live.

Virga

by Kay Ryan

There are bands
in the sky where
what happens
matches prayers.
Clouds blacken
and inky rain
hatches the air
like angled writing,
the very transcription
of a pure command,
steady from a steady
hand. Drought
put to rout, visible
a mile above
for miles about.

Where Were You – Britt Quiroz

So where were you the day that everything changed?
Were you runnin' your mind, or runnin' somewhere late?
So where were you when you thought you lost your way?
When all you want is answers, but nothing came your way.

Fight or flight, do or die.
Never get it 'til it gets you, and all you ask is why.
Take a day one at a time. Your story isn't over and it's all about the climb.

So where were you the day everything changed?
What's meant to break you, will be okay.
So where were you when everything you knew was gone?
And you replay every moment of where it all went wrong.
So where were you? Saying no I can't do this.
You knew that if you gave up, it was a life you're gonna miss.

Fight or Flight, do or die.
Never get it 'til it gets you, and all you ask is why.
Take a day one at a time. Your story isn't over, and it's all about the climb.

So where were you the day that everything changed?
What's meant to break you will be okay.

Grieving's not a weakness, nor pain your enemy.
The battles are reminders of who you're meant to be.

Fight or flight, do or die.
Never get it 'til it gets you, and all you ask is why.
Take a day one at a time. Your story isn't over and it's all about the climb.

So where were you? The day that everything changed.

What's meant to break you will be okay...

What's meant to break you will be okay.

Hot Water Test – Art Alexakis

My doctors told me that I had a disease.
I will slowly fall apart until there's nothing
left that looks like me
I smiled at people as I walked to my car
to call my wife
I told her everything the doctors had said,
then we both began to cry

She said, "Easy can be hard to do."
"Life can be ugly or beautiful and new."
"It's up to me, and it's up to you."
She said, "Heaven isn't hard to see."
"It looks like life with a family."
"In this house that we call home, I will never
leave you."

I take my shots and I walk the walk
in every kind of way
I look for a balance in the things
that get harder every day
I'm afraid I will never be the man that I used
to be
I'm afraid I will never be the man that I want
the world to see
When it looks at me

I know, easy can be hard to do
Life can be ugly or beautiful and new
It's up to me to do what I have to do
I know, heaven isn't hard to see
It looks like life with my family and me

In this house that we call home
I will never leave you alone

I will never leave you
I will never leave you alone
I will never leave you
I will never leave you alone

I wanna go in my own time
I wanna find a brand new loud
I wanna feel safe until they put me in the
water
And the truth comes out

Oh, happy can be hard to find
The puzzle makes sense when the pieces fall
in line
I'm teaching myself a new way to live my
life

I know, easy can be hard to do
Life can be ugly or beautiful and new
It's up to me to do what I have to do
I know, heaven isn't hard to see
It looks like life with my family
In this house that we call home
I will never leave you alone

I will never leave you
I will never leave you alone
I will never leave you
I will never leave you alone

Light of a Clear Blue Morning – Dolly Parton

It's been a long dark night
And I've been a waitin' for the morning
It's been a long hard fight
But I see a brand-new day a dawning
I've been looking for the sunshine
You know I ain't seen it in so long
But everything's gonna work out just fine
And everything's gonna be all right
That's been all wrong
'Cause I can see the light of a clear blue
morning
I can see the light of a brand-new day
I can see the light of a clear blue morning
Oh, and everything's gonna be all right
It's gonna be okay
It's been a long long time
Since I've known the taste of freedom
And those clinging vines
That had me bound, well I don't need 'em
Oh, I've been like a captured eagle, you
know an eagle's born to fly
Now that I have won my freedom, like an
eagle I am eager for the sky
And I can see the light of a clear blue
morning
I can see the light of brand-new day

I can see the light of a clear blue morning
Oh, and everything's gonna be all right
It's gonna be okay
I can see the light of a clear blue morning
I can see the light of brand-new day
I can see the light of a clear blue morning
Ooh, everything's gonna be all right
Everything's gonna be all right
Everything's gonna be all right
It's gonna be okay
And I can see the light of a clear blue
morning
I can see the light of a brand-new day
I can see the light of a clear blue morning
Ooh and everything's gonna be all right
Everything's gonna be all right
Everything's gonna be all right
It's gonna be okay
I can see the light of a clear blue morning
I can see the light of brand-new day
I can see the light of a clear blue morning
Everything's gonna be all right
Everything's gonna be all right
Everything's gonna be all right
It's gonna be okay