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*University of Vermont*

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ANKYLOSING SPONDYLITIS & CHRONIC PAIN SYNDROME:  
BRIDGING THE GAP BETWEEN PERPETUATED MEDICINE & HOLISTIC  
THERAPIES

A Thesis Presented By:

Jarett C. Chizick

to

The Faculty of the Graduate College

of

The University of Vermont

In Partial Fulfillment of the Requirements  
for the Degree of Master of Education  
Specializing in Interdisciplinary Studies

May, 2015

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## ABSTRACT

Ankylosing Spondylitis (AS) and Chronic Pain Syndrome (CPS) can be treated in many different ways. I found a problem in the balance of healing modalities surrounding diagnosis and care of illness and disease. This struggle is not singular to AS and CPS, but universal to physical and mental concerns. Some effective treatments and therapies are not recognized as such or are just beginning to become so. The scope of my work reflects on the course of my life. It was heavily influenced by the way my medical care was managed from an early age and how it evolved over the years. Through my educational program, I examined the necessity to bridge the gap between treatment paradigms and to expand on a broader, more inclusive, healing rubric. This rubric includes a broader emphasis on skill-based and complementary and alternative medicines. The viability to incorporate holistic health therapies earlier in life is explored through my use of the Scholarly Personal Narrative (SPN) qualitative research method. I chose this methodology because scientific fact could be argued either way for one therapeutic approach over another. By incorporating lived experience through SPN the union and cohesion necessary in all healing modalities, and their positive aspects, can be seen. The truth becomes self-evident.

The results of this examination showed awareness earlier in life toward alternative and holistic treatments being paramount. Parents and educators lack information concerning modern therapeutic approaches. It also showed each situation will vary, but choice in treatment for ailments and illness of all kinds is not only viable, but highly recommended and researched. Access issues such as health insurance remain obstacles with some treatments and therapies, while others are a matter of cost prohibition, such as nutrition therapies. The implications of my work indicate a need for earlier incorporation of holistic healing programs and skill based therapies alongside perpetuated medical models in early childhood development and education.

In conclusion, awareness towards medical concerns and how we as a society treat them can be improved upon by systemically incorporating less harmful therapies earlier in life. Fostering relations between medical providers, care providers and educators for students' wellbeing should be the foreground of any educational policy. Educators and parents alike should be made aware of and take advantage of effective skill-based treatments before a physical or mental condition surfaces or medication only approaches are authoritatively recommended. Integrating programs that build strong mental resilience and focus on youth development and education can reduce the necessity for more invasive treatments or medications should an ailment or illness develop.

## **Acknowledgments**

To Love, may you ever be present in all your infinite forms and narratives to all people. May those who seek you find you and those who continue to build walls against you find peace, hope, and sustained happiness with themselves and the world around them.

To my parents, for the unconditional love shown to me through all of my successes and confusion, wherever it might lead.

For all my friends and family near, dear or departed, I will keep writing with plenteous love.

To my undergraduate professors and care professionals, thank you for your patience with a dragon being let out of its cage. My debt of gratitude is indescribable in words.

Dear Robert, Sydnee, Vanessa, Jennifer, My Classmates, Tom Sullivan, Clarence Davis, Anne Pugh, Fiona Patterson, Anthony R. Quintiliani, Lane Manning, The Graduate Student Senate, The Burlington and UVM Communities, Neighbors, Friends, The Universal Design Lab at UVM and the Writing Center... To All Who I hold dear in my heart but cannot name... Three words and a brief explanation: "Thank You, Sincerely." I've always signed e-mails and letters from early years with "Sincerely." It has always been a way to send off my writing with a blessing and my love.

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## **Chapter 1: Introduction & Methodology**

A journey through Ankylosing Spondylitis and Chronic Pain Syndrome has not been explored through Scholarly Personal Narrative before. Over the past two years I have examined various modalities and vantage points on ‘cure.’ My struggle is not a singular struggle, but one that spans other illnesses, diseases and diagnosis and the people they affect. The wisdom I have gained through my educational endeavor has value to the current generation and all upcoming generations. It will assist in respect, appreciation and care for the general quality of life all individuals have a right to live. For me a balance must be struck between inactivity and activity or my disease ‘flares up.’ Writing is a way that I can make sense of the knowledge I have acquired over the span of my lifetime. The wisdom I have gained through my educational program has been particularly instrumental. I write my way to meaning, moving forward with my illness.

To put things simply, I will give a quick synopsis of ‘Life’: I enjoy the company of those who do not take themselves too seriously, but take seriously their purpose and relationships in life. Assisting others reach their true potential, by meeting them where they are, supporting them to find true meaning and value in their actions through all endeavors can shatter the fabric of time. In essence, the constraints on the imagination are lifted. With a supportive environment, knowledge can turn into a malleable adventure of growth. This growth, this love of learning (scholarship), has always been the answer for me. It has always been the key to healthy families, relations and supportive communities.

My journey has proven this true through my wellness, master's degree education and recovery journey with Ankylosing Spondylitis and chronic pain.

As a meaning-making mentor and educator, my story matters. Its credence must be acknowledged first and foremost by me before I progress forward. This is imperative to assist others. It is my hope to gain their trust while supporting them to find what Blasé Pascal would surly describe as a 'personal journey of self-discovery.' Exploring the 'cures' that lie out there in the world, I know the numbing affect and long term side effects some pills and treatments have are not the answer for long-term care. I had to come to this conclusion myself before exploring alternative modalities and sharing the results with others. I want to be a trustworthy steward to my community and the human species. *Experdto Credite* (trust me), "You cannot sedate, all the things you hate", Marilyn Manson sings in a song called "Dogma" on Portrait of an American Family. This rang true in my life through the manifestations chronic pain took root, shape and form. If something does not fit the mold of "normal" it does not give anyone the right to try to anaesthetize it without fully understanding the underlying cause. The long term effects of medications are too detrimental not to find a balance earlier in life for 'chronic care.' Embracing the underlying cause and treating it with the least harmful treatment available should be the objective in all health professions at the earliest time.

Finding and treating the cause, not the symptoms, should be the goal of healing. Briefly, I had three major misdiagnosis in my life which helped me to see the balance needed in the medical field. It was well over ten years before a proper diagnosis was made. Through forms of exclusion, isolation, self and other bullying, cycles of chronic pain led to

destructive patterns of behavior. These included poor coping skills and self-medication. I allowed poor nutrition, stress, my undiagnosed illness and how I perceived other's thoughts of me to erode my self-confidence and faith- almost to the point of death. As the Latin phrase *Experdo Credite* implies, Trust in me does not always imply or indicate faith in others. I had a struggle with my care providers when their recommendations were ineffective at best. I knew there had to be a better solution. My answers were not working. Through my life I have seen how trust and faith can wax and wane. But the one thing that has remained constant over the years is love within the human spirit and its resiliency. I trusted there was a balance between the medications, skills and holistic therapies. It would take years for me to find the right care providers and foster the relationships to find out what that balance looked like.

February 15<sup>th</sup>, 2014, I received a letter from my mother. It was a card misplaced by the Postal Service arriving a day late. Carrying with it was a simple reminder, "Love is the best medicine" with a short little story. She gently reminded me of a time when I was young. My parents wanted to take me on a surprise drive. The day before we had visited a family friend's home who was hosting an AFS (American Field Service) student from Sri Lanka. My younger brother and I measured our heights on the pantry doorpost as we did every so often. I thought nothing of it, though I had grown an inch. I found myself objecting to the drive the next day after having conversations of civil unrest and protest in a land far far away. I wanted to go back and continue our dialogue, plus I really didn't like surprises at that point in my life. The story from the card reminded me of memories

when I was not as trusting of my care providers and when treatments were not effective in my life.

I was not expecting what was to come that day as a child... I loved rollercoaster rides. I remember being right at the height you could go on both the 'kids' coasters and the 'adult' coasters. I had been waiting a long time to try the larger roller coasters alongside my older brother and sister. My older brother would soon be going back off to college at Rensselaer Polytechnic Institute (R.P.I.) and my sister would be leaving for her senior year of high school as a foreign exchange student in Japan. It turned out we were going on a drive down familiar roads on this surprise drive. I remembered the roads quite well. As we were coming closer to our destination, I insisted we were going back to an amusement park from my youth. My initial hesitation had turned into ecstatic joyful jubilation. I would finally have the opportunity to enjoy the thrills of the coasters alongside my older siblings.

And so it is with 'Life' and chronic pain. The ups and downs are ever present like a rollercoaster or the change of the seasons. It would still take me years to understand the old cliché 'Never judge a book by its cover.' Or in this case, "Never judge a surprise journey by your initial hesitation." I could not understand then that my hesitation was brought on by stress reactivity within my body. The genomic expression of my autoimmune illness already beginning to take shape and form causing pain. It still takes constant reminders from friends and family to "Be Love", show kindness and show jubilation in my relations throughout the growth process called 'education', better known as 'Life.' And so I write. I write to educate others on the importance of identifying what

may cause genetically expressed illnesses earlier in life and how to build resiliency toward the throes and tumult daily life may bring along the way. Regardless of what ailment or diagnosis one might ‘come down with’, attitude and relationships foster the ‘care’ and ‘healing’ process.

**Dear Robert:**

Sitting here writing today my apartment is a mess. My desk looks like a tornado came through and nothing seems to be where it belongs. I had trouble addressing this just to you. As you know this journey has not been just about the learning I have done on my own or from one individual nor class. This thesis is correctly addressed to everyone everywhere, but mostly you, your co-professors: Jennifer, Sydnee, Vanessa and my care professionals, policy makers, and loved ones. The knowledge and wisdom I gained from my peers inside and outside the classroom is also considered through my thesis. I cannot leave out Professor Patterson, Anthony Quintiliani, Ph.D LADC, Vicky Colvin, Ann Pugh, Miv London, Magdalena Naylor and many others who educated me along this journey. Without their care and support, I would not know the meaning of ‘true’ healthy relationship building and fostering.

As you know, before I entered the Interdisciplinary program I was in a very precarious situation. It was a time where I felt lost and stumbled over my own feet. The path of life seemed incomplete like the highways of New York State in my youth, always under construction. Questions like: “How did I get here? What is my role in life? If this is where I am and that is where I want to go, how do I get there?” constantly resurfaced.

These questions and many others were tripped up by the situation or what some people call 'their lot in life'.

I am reminded of the quote from the Terminator movies by the character John Connor, "There is no fate but what we make." (Terminator 3) The choices and freedom we seek is deep within our souls, or consciousness depending on what we believe. I am only limited by my imagination. No constraints, societies or the world in which we live can ever repress my inner being, my inner peace or the way in which Love communicates. I believe the mind and heart are intertwined with the soul (or consciousness). Limitations and inhibitions are only in my mind. Through meditation and prayer I can literally 'train my brain'. Science has proven this through changes in neuroplasticity and specific video game 'training.' In fact, Jane McGonigal designed a video game specifically to help fight challenges like anxiety, chronic pain, and depression called "SuperBetter." ([janemcgonigal.com](http://janemcgonigal.com)) All of our lives are truly undefined. Make your thoughts reality. Narrate the story of your life. Define your own normality. This is the life I am writing. With courage, I intend to show the harmony in 'chronic care.'

Like a captain on a ship surviving stormy seas I never thought my life could serve any practicality. Looking over the past four years of my life it was difficult to see the synchronicity. It wasn't until I felt my life had no direction, purpose or meaning, that I found my vocational call. Martin Seligman defines vocation as, "being called to act rather than choosing to act." (Flourishing, Page 75) I knew I was being driven toward something at the time. I could feel a draw, a pull deep within my being. I just did not know what it was. I found myself applying for a continuing education course to achieve

my MBA. I thought this was my 'calling.' Extenuating circumstances drove me to choose another bearing. Through conversations and life situations I discovered the Interdisciplinary Program. Sitting in the Fireplace Lounge, I found myself chatting with a man I knew almost nothing about. I had been referred to him by some colleagues and alumni of my undergraduate alma mater and professional service staff at UVM.

Before the conversation, I did some research and read up on this fellow. Sitting across from me was a published author, scholar and philosopher. I was nervous, scared like I was treading water. Never in my life had I been so intrigued by the style and format of this program he had conceived. I knew later that day my life had been forever changed. I felt a drive and push toward the program for the knowledge I knew I would receive. It reminds me of Ann Lamott's words, "...it feels so great finally to dive into the water; maybe you splash around and flail for a while, but at least you're in... you're afloat, and you're moving." (bird by bird, Page 63) The proof is here before you as a published story author, as a precursor to my journey, and this thesis. I would not be here today without the motivation, support, and encouragement of a stranger, now a friend.

A master's degree in interdisciplinary studies seemed like a pipe dream. Where else would I be able to explore the dynamics of social work, human rights, different forms of medicine and how they all intertwine? This illustrates a major point in my thesis: unconditional generosity, kindness and compassion of family, friends, strangers and community. Their love and support through life's journey is what can assist anyone to make progress in life to move from coping to managing any situation or circumstance, be it illness or a 'normal' walk in life. It certainly supported me to overcome myself and my

perceived limitations from the past. The learning through the program assisted me in fostering my relationships with all of my care providers, 'western medicine' and holistic alike. In the process, it helped bridge the gap they themselves had between the two as they saw the improvement in my condition.

Mind you, Robert this is an ongoing process. If there is one thing that is certain in life it is that 'change is inevitable'. I believe Darwin said, "It is not the strongest of the species that survives, but the one most responsive to change." Throughout this process, I have had to show my resilience, my courage of character, ability to let things go and roll with the flow. And as you constantly remind me Robert, "Do your best and let the chips fall where they may." Similarly I wake up every day and am reminded of a phrase by Gandhi, "You must be the change you wish to see in the world." It hangs on my bedroom door as a constant reminder to 'do my best' in all that I do.

Through the Interdisciplinary Program and the classes I took, I was able to explore how best to manage change, facilitate relationship dynamics and to be myself without regrets or compromise at all times. The style of research writing known as Scholarly Personal Narrative (SPN) helped me find the personal relevancy in the academic rigor and vigor, pushing myself to new limits. Our classroom formats based on the principles of 'moral conversation' truly brought out group vibrancy. They allowed me to explore my chronic pain, stiffness and soreness without it being the 'dominant voice' in my head. The strength in shared stories and vulnerability added to the cohesiveness of my growth and learning experience as well as my peers.



This picture is the briefest definition of ‘moral conversation’ I can come up with as it is founded in acceptance, care, respect, and understanding. It was taken at an old family friend’s lake cottage on a trip to my hometown. The serenity of a Lake Ontario sunset and the belonging of family reminds me of the unity we all share.

**What is (e)SPN:**

“I write, therefore I am” - Robert Paraphrasing Descartes (Liberating Scholarly Personal Narrative Writing)

Dear Robert and Sydnee,

“What have I learned about Scholarly Personal Narrative and why does it apply to my thesis?” Within my reading, writing and course work if there is one thing I have learned about the Scholarly Personal Narrative (SPN) research method it is that it is always evolving, ever-changing and no two manuscripts or writings are ever the same. I learned this through reading *Liberating Scholarly Personally Narrative Writing* (Nash). If anything, some Scholarly Personal Narrative Writers (SPNW), even Epistolary Scholarly

Personal Narrative Writers (eSPNW), build off of one another, learn from one another and create unique documents strategic to their particular area of study.

In *Me-Search and We-Search*, Robert, you give credit to Christian L. Berry for creating the eSPN format, simply known as letter or message writing throughout an SPN piece (Nash & Bradley, Page 137). As I write what I have learned about SPN, I realize that my thesis may become more of an (e)SPN to educators, parents, policy makers and medical providers. Though it is one document, it may have many messages and letters within the overall theme. Writing my thesis on *Ankylosing Spondylitis and Chronic Pain Syndrome: Bridging the Gap Between Perpetuated Medicine and Holistic Therapies* has many themes and takeaways for those who read it.

In writing this document I must be mindful of a ‘cardinal rule’ I have learned: “Write from the heart. Go in before you go out.” Sydnee, Robert frequently reminded me of this in our classroom discussions and personal correspondence. I must remember that within the scholarship, my narrative and how it relates is what matters. “It’s all about the stories,” Robert will say to me and my classmates (Nash & Bradley, Page 22 & 27). When analyzing these very important components in my eSPN writing I need to explore deep inside myself. There must be the “I” in my writing before I search outside myself or a term I like to use “Otherfy” or “Otherfry”. Robert has told me this in another fashion, “Describe, don’t prescribe.” This must be a part of every eSPN writer’s ‘code of ethics.’ It is similar to our courses and classes where ‘moral conversation’ is used. To utilize a departure from Robert’s words “explore the truth in what you oppose before preaching the error in what you espouse.” This is the basis behind ‘moral conversation.’

Robert and Sydnee, using moral conversation in your story telling and (e)SPN writing can be rewarding both as the author and the reader. It can help you find insights you never knew about your perspective and your meaning-making journey. It can enliven the scholarship and bring forth ‘true’ knowledge and wisdom for yourself and others. When I look to the errors I have told myself over and over in my story instead of automatically defaulting to the things I have told myself from my personal perspective, it opens my writing so I can see from multiple vantage points. This is similar to modifying an old Confucian saying, “The man who moves a mountain begins by carrying away small stones.” From my vantage point, I say, “Become the mountain, there is no need to move it.” This allows multiple perspectives to be viewed at the same time. Consensus is thereby easier to be attained by me and thereby the reader. It is my hope the takeaways from this document further the discussion on the best ways to bridge the gap in holistic care and perpetuated medicine for our future generation’s sake.

Within this perspective, I’d like to give you an example. It comes from the Dude De Ching quoting the Tao Te Ching:

“Tao bears love;  
Love bears restraint;  
Restraint bears acceptance;  
Acceptance bears the World;  
All things begin with love and end with restraint,  
But it is acceptance that brings harmony. As others teach, I teach,  
“Those without harmony end with violence”;  
This is my teacher.” Page 69 (Kindle for Android Version)

The point behind this is that it allows for similar personal meaning making in all things. SPN can explore everything from organized religion, spirituality, science, and any

educational rubric, growth or learning process. It also allows you to utilize research methodologies building off what others may have already done or create an authentic master piece or a hybrid somewhere in-between. It allows me to be me and you to be you, but together we can learn from one another through the multiplicity in respectful engaged pluralism in mutuality. All of our combined life experience increase our knowledge pool, even if we do not see eye to eye on all matters. It is the growth from the shared exchange of information that is imperative.

The stories and learning will be different as well as the scholastic topics. One thing is for certain: SPN takes both knowledge and experience. I can write about my stories all day, but if I just sit around and write, eventually I'll have nothing to write about. There needs to be balance. My thesis will examine both the research, scholarship and my stories. Thich Nhat Hanh believes that the "I" in the Statement, "I am the way..." could be interpreted as life itself. Therefore, "Life is the way." Changing the epigraph of this letter: "I write, therefore I have life." And where there is life there is also love. Through actions and choices my stories comes to life with scholarship in this thesis. I can live the maxim: "I have Life, therefore I love." And hopefully educate myself and others in the process. (Living Buddha, Living Christ, Page 55)

I wish I could have had this experience when I was twenty-two or eighteen. My story then looked more like movie scripts and fiction tales. I remember what H.D Thoreau once wrote, "Gardening is civil and social, but it wants the vigor and freedom of the forest and the outlaw." Referring to writing here, civility should be shown in how I tell my crazy tales with academic rigor and vigor. It is through both Hanh and Thoreau the passion for

writing and educating emerges. How can one write if one has not lived, yet how can one live if one does not write one's own tale? Putting the two together is the intent of my thesis. I intend to show the balance in natural care and perpetuated established medicines. My story intertwines both in a very real way.

The above is meant to serve as a further example of what I've learned about (e)SPN and why it is used for this thesis. My scholarship needs to serve a purpose. Quote dropping is useless unless I describe their meaning with my stories and the thesis narrative. It is a fundamental requirement to go from the 'me'-search with the research striving to achieve the 'we' search for the reader. The narrative through line, theme and hooks can never be forgotten...

There may be times I stray and tell a personal story. That's ok, this is (e)SPN. I must be mindful to bring it back and have relevance to the scholarship and point to the reader. When looking at personal stories, it's always important to look at specific details. Is there anything from the specifics I could generalize or universalize without losing the zest? What can the reader take away from the story? The scholarship? The lessons? This is important for me as an author to recognize. Do I need to reveal all the details of the individuals in my life who may be personally invested in the tales I tell? These are all key components of the 'pre', 'me', 'we', and research of (e)SPN . Some of the stories that coincide with the scholarship will be directly related to me. Others will be of individuals I have personally interviewed or am related to. Names will be changed for both their and my sake.

Reviewing the essence of this research method Robert and Sydnee, I know it is the best way for me to present my thesis. Incorporating this research method and pedagogy into any workplace or educational center can complement current and traditional modalities. The takeaways from my thesis allow expansive growth opportunities in education policy and medical practices. It also leaves room for further analysis, exploration and others to add their stories with their scholarship. The eSPN process is tried and true backed up by academic rigor and professional vigor in the field. I chose to write my thesis in this format because of the courage it takes. For some this writing style will fit like a glove. If I could be so bold, for those who may not have tried it, give it some time within your writing style, storytelling and scholarship. Truly, all you need is a little bit of love and patience.

Sincerely,

Jarett Chizick



Peace for me is the balance in the ups and downs, the lefts and rights, the side to sides in life. Health is simply the balance in how I manage the care I receive, medically, nutritionally, physically and emotionally/spiritually. Love is all encompassing from philia to agape from the people in my life. It takes caring, supportive, relationships to make all of this possible. (Quote: H.Jackson Brown Jr., "Life's Little Instruction Book")

## **Chapter 2: Chronic Care: The Human Condition**

“There are many who seek knowledge for the sake of knowledge: that is curiosity. There are others who desire to know in order that they may themselves be known: that is vanity. Others seek knowledge in order to sell it: that is dishonorable. But there are some who seek knowledge in order to edify and love: that is teaching. [I dare say living-Educating.]” – Bernard of Clairvaux

Through the course of my life I have sought after many things. The first of these is the socialized attainment of wealth and fame. It was not until I realized I had a new full-time job of caring for a chronic condition that I knew I had to change my outlook. I had to redefine my life and my definition of wealth and fame. Bernard of Clairvaux’s statement was written in *How Stories Heal: Writing Our Way to Meaning and Wholeness* toward the conclusion of a chapter I had a letter published in (Nash & Viray). Telling part of my story in that manner was healing. The return to my hometown area reminded me of my youth and upbringing. Most there know what I have gone through. My interaction with parents and children was mutually educational. It reinforced to me the balance and earlier educational collaboration still required for those who will eventually be diagnosed with a serious ailment of any kind. It also showed the kindness from others and self-compassion that is needed in the developmental and growth process of an individual’s life span.

### **Dear Educators, Parents, Policy Makers and Medical Providers:**

It is normal for any child to become ill. It is also normal for any adult to become sick. What is typically not ‘normal’ is individuals to perceive a lack of physical, mental and psychological wellbeing as part of early childhood education. When I was six years old

and diagnosed with ‘growing pains’ the doctors left my complaints at that. The mental and psychological training for resiliency to face the upcoming diagnoses of Chronic Fatigue Syndrome and then Ankylosing Spondylitis (AS) would be left up to my parents, my religious center and my extracurricular activities. I point this out for a simple reason. The genetic marker, HLA B27 for AS is now common knowledge and easily tested for. It is more common than Rheumatoid Arthritis, Cystic Fibrosis and Lou Gerhig’s disease combined (Spondylitis Association of America, SAA).

Most ailments of genetic makeup can be tested for at an early age. This is not to say everyone that tests positive for these markers will eventually ‘contract’ the ailment. This is the case with AS. More than 10% of individuals who test positive for the genetic marker never develop signs or symptoms of the disease (Revellie, et al., SAA). What causes some diseases to manifest themselves while others lay dormant? In my case, I know how stress reactivity, nutrition, environmental factors and meaningful activity play a significant role in how my ailment ‘acts up.’ I like to say ‘stress is the leading cause of illness’ and know its role.

AS is an autoimmune disorder where the immune system is ‘hyperactive.’ The white blood cells begin to ‘attack’ the body when there is no cause for ‘alarm’ or ‘foreign pathogens’ present. Personally, I do not like taking the biological agents designed in laboratories, manufactured in factories, shipped in refrigerated trucks to inject into myself. Their role is to ‘calm’ the ‘inflammation’ in my body. I know after years of personal experimentation, diet, exercise and study of the medications: ‘what works for me.’ The typical treatment I utilize now for AS is the least amount of medications, proper

nutrition and regular physical therapy. Finding the right balance in medicine and care providers has been crucial to my health.

I know that any physical or mental ailment can be worked through with the right resources and support system. Training our youth earlier for the potential that a disability or disease might befall them without telling them what the training is for can be advantageous to a society's productivity, quality of life and standards for education in the present moment and the future.

A progressive system in our educational system and societal system should be incorporated to ensure individuals are prepared for any situational outcome that may arise. If a condition is already present, or if a physical or mental concern is suspected, individuals can prepare for the lifestyle they may have to live. It will also allow them to focus on careers and vocations that suit them. This should take place in the school systems and at home from early childhood to young adulthood aiding an individual's dreams and goals. For some, medicine has stifled this process as they have not found out 'what was wrong with them', misdiagnosed them or found out too late how to be of assistance. Most Americans know 'modern medicine' or 'Western Medicine' by those names. I have chosen to call it 'perpetuated medicine' for this paper. The advertisements for the pharmaceutical drugs have been on media for well over twenty years, not including posters, the radio and historical contexts. I propose, through my own life experience, a balance in the educational and health care systems that involve less invasive treatments and therapies; more than pills and injections alone. I also implore people to know their bodies and get second opinions for the best possible care. Perpetuated

medicine is catching up to a more balanced approach to diagnosis and treatment, but our educational system and societal structure is lagging behind.

**Dear Parents:**

I make this plea to you first and foremost because any educator, policy maker or medical provider is a parent to something. For the most part, they know that a balance in these treatments is necessary for their own wellbeing. So I reach out to you. The system we have in place in our schools and health care system is not necessarily broken. It does need tweaking to fix the inconsistencies perpetuated by those who would proselytize one way of thinking versus the polar opposite way.

Going through my struggles with Ankylosing Spondylitis (AS) and Chronic Pain Syndrome (CPS) I know there are times perpetuated medicine is the necessary stimuli to start the healing process. But the caring nature of alternative therapies is ultimately the cure for a system of chronic care. I know that the medications, though necessary for the acute (one week to ten years) may be necessary, ultimately, most of the side effects outweigh the benefits for me. Currently, I have not been taking the TNF inhibitors (tumor necrosis factor alpha inhibitors) for well over two years. These medications are designed to block the inflammatory response and theoretically decrease the body's overactive immune system (enbrel.com). They are also designed in a lab, produced in assembly line fashion, shipped on refrigerated trucks and injected subcutaneous. I know that with continued use of proper diet, mindful activity, exercise and meaningful work, the drugs are not necessary.

Recently, I was involved in some traumatic life events and have let these things slide. Because of it, the evidence is clear, I may have to go back on the medications for an acute time to ward off the effects of the waxing and waning of my inflammation and pain. A study on the biological agents proves what my life experience already knows. *Effects of Anti-TNF Alpha Drugs on Disability in Patients with Rheumatoid Arthritis: Long-Term Real-Life Data from the Lorhen Registry* by Filippini, et al. shows the effectiveness of these medications during the first year and reduced effectiveness over the subsequent four years. With an individual's increased ability to move, decrease in stiffness and pain, the medication can plateau. They did for me. I was able to wean myself off of the medication going from weekly injections to bi-weekly to monthly to none. There are no long-term studies on these medications as they have only been out for about ten years. I know it is possible to take a 'booster' or the minimal amount of the injections (bi-weekly or monthly) if the exercise, nutrition and meaningful activity is incorporated. With them in place, as stated, I was able to stay off of the TNF inhibitors and the more invasive therapies (corticosteroid shots) for over two years. This is significant as perpetuated medicine would have you believe you need to take medication on a more frequent basis.

**Dear Educators:**

Your job may be the most difficult as you are caught in the middle of the crosshairs between parents, policy makers and medical providers of all kinds. You are one of the major structural beams in the bridge of communication. Regardless of what policy mandates and what parents neglect to teach, you will spend a significant amount of your time engaged with individuals of all ages edifying intellects and stimulating senses

toward a fruitful end. Your responsibility is the same as mine: To educate educators and policy makers for the benefit of all with balance, compassion, humility, kindness and your personal definition of ‘Love’ or ‘care.’

As a child I was riddled with chronic pain that no one could diagnose. My parents are both educators with their master’s degrees. They took the best possible care of my condition while listening to the advice of the medical professionals and educators in the area. It wasn’t until I outgrew the initial diagnosis of ‘growing pains’ that more attention was paid to my illness. Doctors in the area were perplexed by an outbreak of an ailment known now as CFS or Chronic Fatigue Syndrome. My current care professionals tell me this is a diagnosis of exclusion when no other cause can be found. Personally, I disagree. I know these individuals and the effect the disease had on their lives and still does.

It may be true that the ailment is a last resort for physicians to diagnose someone with, but the fact remains, many suffer from this illness. For these individuals, something else could be going on with nutrition, exercise, meaningful activity or a diagnosis not yet found. Yet the disease is very real to those effected and recognized by the Center for Disease Control (CDC). In my case, though diagnosed, the cause would not be found out for another ten years. My mother was strongly against the medications provided to me for my CFS. She opted for nutrition and an active lifestyle. One medication seemed to work when all else failed, Doxycycline. Used to treat bacterial infections, it seemed to work to clear up the most irritable symptoms of CFS. I remember one occasion when I had a severe ear ache and was feeling horribly lethargic. My mother insisted the doctor give me a dose of Doxycycline over the weekend and things cleared right up. This was a surprise

to the physician. Of course the medication could have been a placebo effect or my body's natural ability to fight off the illness, but it worked.

This communication between my mother and my care professional started a cycle of how I understood the relationship between holistic and perpetuated medicine. I knew that the activity level I was engaged in and the natural foods I was eating were helpful to ward off the effects of CFS. The medication was only used as an acute measure for a short duration. This is an important point for educators of all kinds. I have written it before, but it cannot be overstated, "Pills are not skills." I know their uses and when they are appropriate. For the most part, I understand that a healthy living environment, active lifestyle (however that looks for the individual) and proper nutrition are keys to warding off illnesses and stress reactivity of all kinds.

They can be the key to early detection of illnesses or conditions that may manifest later in life. As educators, it is imperative to recognize when someone is in a situation where one of those three is out of balance, before medications are used. Early detection of genetic markers for illnesses that will require acute medications at some point in life can be helpful. What is more effective is what is known as 'Flourishing Psychology', formerly called 'positive psychology.' The resiliency training involved spans all walks of life and lifestyles. Keeping individuals on the positive or at least the neutral side of the 'Sine Wave of the emotional rollercoaster of life' is not the goal of medication for physical or mental concerns. At best medications are used to calm inflammation, 'correct' an imbalance or kill a foreign pathogen. Teaching the skills involved in coping and

managing the negative side of the Sine Wave of life, whatever they look like, is the ultimate goal of an educator.

If a person cannot handle the downturns or upsets of life with a positive outlook, how are they to be a productive member of society or enjoy a 'high quality of life'? I have found this a hard balance with all the differing, conflicting interests in society. From the search for the 'perfect job' to the search for the 'perfect support networks and relationships' this in and of itself can cause undue and unhealthy stress reactivity for someone with a chronic ailment. Through the course of my master's degree program I have found it is the connections we build and the relations we foster that lead to the 'finer things in life.' Managing the balance in nutrition, exercise, meaningful activity and my healthcare needs has become easier because of resilience training and 'flourishing psychology.'

“Perfectionism is one way our muscles cramp.” [Both our physical and psychological muscles.] – Anne Lamott – *bird by bird* (Page 30)

Striving for the 'perfect balance' in my healthcare and personal needs has often gotten in my way. There were times I would make positive steps in my healing journey only to find I had neglected key aspects of my care. I might find myself relying too heavily on medications and not nutrition or find myself neglecting my physical therapy. The negative self-talk would start rattling around in my head, “You're not doing this correctly, you're not doing this right...” Reading and researching my own illnesses and disease I came across a program called the Masters of Applied Positive Psychology at the University of Pennsylvania. One of the interesting things I found while reading the book *Flourishing* by Dr. Martin Seligman was the 'Losada ratio.' I have tried to turn most of

my interactions with individuals into the caring and understanding relations that last by having a 5:1 ratio of positive interactions to negative ones, including self-talk (Flourishing, Page, 67). This is the 'benchmark' for long-lasting relationships whether in a marriage or constructive business partnership. Having a disease which literally 'saps' my energy on a daily basis, I have to be mindful of each of my interactions so my disease does not 'push' people away. As educators, this is important to realize as AS and Chronic Pain Syndrome effect individuals differently than others.

Imagine for a second that you are having a parent teacher conference with a divorced couple about the behavior of their child in the classroom. Each parent has a different perspective on how the situation should be handled. Managing AS and Chronic Pain Syndrome on a daily basis is fifteen to twenty minutes into that conversation when no headway has been reached and neither party is willing to listen to any recommendations to improve their child's academic or behavioral concerns.

This is also how I have felt in the past fostering my relationships with my medical and care providers. We had to work together to educate one another on the balance for my individual needs with medications, diet, exercise and alternative therapies that work just as well as the acute and chronic medicines available. As educators, it is imperative to know each students wellbeing should be the foreground of any educational programing. This balance in communication between parents, policy makers and medical providers is an educator's responsibility above and beyond any other. An educator has too much interaction with students and parents' children for this not to be a major source of educational programing in the future. I know if wellbeing and balance in my health was

emphasized in my educational learning as a youth and the information available now was available then, the stigmas attached to my disabling diseases would not be perceived as bad. Educational policy would also incorporate this information into curriculum earlier.

**Dear Policy Makers:**

“Should Wellbeing Be Taught In Schools?” –Martin Seligman, *Flourishing*, (Page, 79)

The short answer to this question... Yes, and it already is in some parts of the Country, better in some parts than others. The real question lies in how to implement it across the Country, standardize it in a way that a majority of individuals can agree upon and use terminology that is not ‘offensive to portions of the population.’ Let’s break that down into its parts. I know by participating and researching programs like the Mind Body Medicine Program at the University of Vermont that Resiliency training similar to PENN’s Resiliency Program (PRP) and Jon Kabott-Zinn’s Mind Body Stress Relief Clinic actually have these results similar to a quote from *Flourishing*: “PRP promotes optimism by teaching students to think more realistically and flexibly about the problems they encounter.” (Page, 81) By assisting students with critical thinking skills, problem solving skills, and teaching them to quiet their racing thoughts such programs actually increase the effectiveness of the body’s natural healing process, increase the ability to function under stress, pressure and increase joy, happiness or simply ‘quality of life.’ Working this semester at the Research Center for Children, Youth and Families at the University of Vermont, I know the research is there to aid in treatment once a diagnosis is made or perhaps prevent one from being given. Certainly, there is a case to be made for reducing medications given for ADHD and other concerns to six to twelve year olds...

I know these programs have worked for me in the past and have worked for me in the present. When I get out of touch with the routine of the skills taught from these programs, I am more reliant on the acute pharmaceuticals perpetuated medicine wants me to be on. When I am actively engaged in the techniques and training such programs offer, I am more productive, my pain levels are reduced and I can decrease the chronic medications which side effects can be extremely damaging to a human being. How then can we get a majority of the population to agree to implement 'wellbeing', 'resiliency training', or 'quality of life education' in schools? Some of the tried and true methods are already out there. No more studies need to be conducted. What needs to be done is a simplistic educational process that these programs may look different in different areas of the Country, but the goals are the same.

When I talk to certain individuals about being involved with 'Yoga.' They have certain ideas in their heads. I have heard things, literally, "Yoga is not for a Christian Nation." and "Meditation leads to Hell." Even after educating individuals on the health benefit outcomes of the techniques involved and the scientific studies to back them up I have heard, "The results are the same as prayer." and "How does yoga differ from what is already done in physical education classes?" These are excellent points and a reason to talk about why the language in policy making is important with these programs.

Empirically, there is no 'real' statistical difference in the health benefit outcomes from focused prayer versus meditation. There is no 'real' statistical difference between individuals intentionally running, biking, walking or stretching for twenty minutes or doing yoga movements for the same amount of time. It is the 'language' that holds some

individuals back from implementation of these programs in school systems or resist them when they begin. For that reason, I know that ‘Mindful Movement’ or ‘Mindful Activity’ are much better terms for ‘Yoga’ when implementing the health benefits that come with such programs for public schools. Resiliency training for AS and Chronic Pain Syndrome would have been helpful as a youth, but my community did the best job they could without all the scientific information we now have available today. With it, there is no reason we have to allow another child to go through three misdiagnosis of illness or have their youth plagued with medical concerns without the proper support systems and networks of care providers. It is possible to have a system in place where resiliency training is a part of an individual’s curriculum and mindful movement and activity is a part of their school day.

**Dear Medical Providers:**

My last visit to the hospital was very interesting. Things have changed a lot since that last visit. I have been involved in focus groups, surveys and have been asked to make recommendations to the board of trustees for a public ivy university involved in public health research. The hospital visit over a year ago consisted of a routine appointment with a follow-up with two different specialists. The nature of the visit was only partially connected with AS and Chronic Pain Syndrome. Most of my providers are at a ‘teaching hospital’ minus the holistic herbalists I see for alternatives to pharmaceuticals. The doctors all had the same answer for me when going through my medication checklist. “That herb is not in our online database and I can’t add it in manually.” I was told in

order for doctors to be trained on all the herbs that have similar effects as some of the medications I take it would keep them in medical school an extra three years. In addition, the database to build it would take at least ten with no one to build it.

To me this was confusing. With all of our medical records now online, I do not see why this is not already happening. Currently, my herbal medications are now on my online medication list as well as the supplements. There is no reason why an individual should not have a choice when a disease or illness is diagnosed in the first place though. Yes, there is a time and place for the pharmaceuticals, the acute pills and the longer term medications can be lifesaving. People should be well informed ahead of time what affect the medications have on their body before they take them. Many, especially the psychiatric medications, can take six months to years for the body to ‘recover’ or come back to a natural state of homeostasis if discontinued. It is also a known fact that many of the psychiatric medications, anti-depressants and a few others are no more effective than the placebo drugs given during FDA approval (Flourishing, 47, studies explaining it 286). The studies cited state only eighteen percent of the pharmacologic effect can be traced to the medications and argue that can be linked to the blind breaking in the control group.

This is common knowledge for me as I have been given everything from anti-depressants to opiates to barbiturates and anti-psychotics (yes, anti-psychotics as ‘sleep aids’). I have researched each one extensively before and during administration. Some of these were necessary in the short term. The anti-inflammatory medications varied. Some were not strong enough or were too strong and needed to be discontinued. The balance in holistic and alternative therapies is key here. Before biological agents were the most prevalent

form of therapy for arthritic conditions, I found a 'better therapy.' Yoga and mindful movement worked. Herbal medications were effective, for the most part and did not have the side effects the non-steroidal anti-inflammatory drugs (NSAIDs) had. When biological agents (tumor necrosis factor TNF alpha inhibitors) came out, they were a 'quick fix' to the necessary intent a holistic lifestyle demands. Come to find out, the biological agents had the same effect as the NSAIDs. They were fine for the short term, but in the long term, they cause more harm than good for me. In addition, the side effects taking them caused nausea, lethargy, and flu like symptoms, sometimes for days at a time. I must state here, that this is contrary to what perpetuated medicine would have people believe as is stated in journal articles like *Effects of Anti-TNF Alpha Drugs on Disability in Patients with Rheumatoid Arthritis: Long-Term Real-Life Data from the Lorhen Registry* (Filippini, et al.) Most of the studies will show an improvement in the first year and subsequent four years, but lack long-term follow-up. As stated earlier, studies are suggesting what I know to be fact, after initial treatment, one year, titration can be reduced if exercise and nutrition (the skills) are improved. Furthermore, the cost of these medications is a small salary, ranging from \$13-17,000 annually depending on whether you utilize a self-injection or infusion method (Cannon GW, DuVall SL, Haroldsen CL, et, al. *Persistence and Dose Escalation of Tumor Necrosis Factor Inhibitors in US Veterans with Rheumatoid Arthritis*). With median income in Vermont at around \$52,578 or a disability income around \$12,960 these medications are hardly affordable (Yahoo News, Poverty Rate Rises, Median Income Falls).

For me, I know that these medications are only for short term use to get back to a mindful routine of wellness. A quick search on pubmed will find similar results of my story. In *Ankylosing spondylitis in an athlete with chronic sacroiliac joint pain*, an initial misdiagnosis led to prolonged suffering in the athlete. The authors ‘urge suspicion and caution when dealing with sacroiliac joint instability and dysfunction because of the prevalence of spondyloarthropathies.’ (Miller TL, Cass N, Siegel C) Many results in this case are similar to mine, including the initial medications which were used. Individuals are shown to be taking the medications with ‘good’ to ‘fair’ results and living ‘productive lives.’ Many though are not able to engage in heavy lifting or harsh physical labor for prolonged periods of time. This athlete was able to tolerate the indomethacin (basically a strong anti-inflammatory drug like ibuprofen) and work a ‘non-heavy labor job.’ In my case, indomethacin caused an ulcer and needed to be discontinued after a few years of use, though it was effective. When a ‘good environment’ is present, the amount and quantity of the chronic medications can be reduced.

Times when I am able to engage in moderate activity are reserved, in my case, for physical therapy, as was the case in the case study mentioned above. They need to be. If I want to stay active and mobile, I need to stay efficient with my productivity. ‘Live life the way you want to live or what is the point in living life.’ That is the way I feel, obviously within reason. My limitations are effected by my illness and I know what the benefits of optimistic choices afford me. The training and the balance in perpetuated medicine and holistic alternatives is imperative now and earlier in the educational

process. It will lead to a more productive workforce, a higher engagement in social activities and a higher quality of life for all.

### **Chapter 3: Ankylosing Spondylitis and Chronic Pain Syndrome's Effect on Life**

#### **Beginning to Understand Ankylosing Spondylitis and Chronic Pain Syndrome:**

Navigating the daily throes of life gives my life meaning for the educational value it offers myself and others. I know the story of my life battling with the inflammation, stiffness and chronic pain has value to others who may not understand the energy level it takes just to keep Ankylosing Spondylitis (AS) and Chronic Pain Syndrome (CPS) at bay. Typically AS and CPS are associated with high levels of C-reactive protein, a protein higher in concentration when the body is fighting off disease and infection than when it is not. Some think there may be a correlation between eating a low gluten diet and reducing inflammation this way. Others disagree. All I know is that when I am eating fresh fruits, vegetables and meats in proper portion sizes and not preprocessed foods, I feel better and my pain levels are lower. A recent study, *Positive and negative affective states and disease activity in ankylosing spondylitis*, confirms “A higher positive affective state was associated with lower values of C-reactive protein.” (Domínguez CJ, Ugalde PF, Vilchez DR, Carretero-Dios H, Estévez EC) Showing positive moods and ‘wellbeing’ associated with lower ‘inflammation protein’ is common.

There is a direct correlation to the nutritional content of the foods I eat and the lower levels of pain associated with my day. Domínguez, et al’s study was examining the influence of psychological affective states in conjunction with disease activity and acute-phase reactant. So of course, when I eat healthy and am in a better mood, I feel better and

my pain levels appear lower. Also, when I eat foods that naturally reduce the c-reactive protein in my body it just makes sense, 'I SHOULD feel better.' Natural foods high in simple sugars and proteins easily processed by the body have allowed me to stay away from the TNF inhibitors for some time. This has only been possible in conjunction with an active lifestyle with mindful activity, holistic therapies and herbal tinctures. Without which, I have had to go back on medications to manage AS and CPS. I do not enjoy the drowsiness the pain killers cause, the digestive problems the anti-inflammatory drugs produce or the amount of my cognitive functioning they take away. No one should have to rely on sleep aids or drink three cups of coffee in the morning just to counter act the medications and pain they experience during the day.

There are many things in my life AS and CPS has robbed me of, not the least of which have been actively participating in sports the way I use to. I have had to modify my activities to suit a new lifestyle around the progression of my disease to accommodate my symptoms. This journey from actively playing soccer for twelve years, skiing and snowboarding for the same duration to only being able to walk or ride a bike has not been an easy transition. During the course of finding the balance between holistic therapies and perpetuated medicine, I went through three long term relationships, two major career changes and now my master's degree. I will not let my ailment stop me from achieving my dreams of joyful living any longer. AS and CPS have taken enough away from me over the course of the last fourteen years. Now it's my turn to get something from this relationship.

Here is how I see the most recent progression of this taking place...

I believe a story would best illustrate my point:

The cool crisp autumn evening surrounded my body. I had just returned from work at a local ski area restaurant as the assistant manager. My back was sore and my pain levels were increasing. The weather was shifting as only the 'New England Air' can. The barometric pressure was falling. The day went from hot and dry to cold and damp without warning like a head-on collision. It was like driving on a curvy country road trying to avoid a deer. Perhaps a picture of a moose would be more appropriate living in Vermont. That was my experience when I first moved to the State years before. Luckily, that first night coming home from work there was no oncoming traffic, just the eyes of the creature staring back at me through the passenger window. With a gasp of panic I swerved back into the correct lane realizing what had just happened. Nights where my pain levels increase are all too often in New England with or without proper care and medication. Just like a surprise experience with a moose driving down a windy road with the chill of autumn my illness can overwhelm me.

One Fall evening, a friend and I had plans to have dinner. She knew all too well how the weather could affect my pain levels. We chatted about life, plans for the future and what the day's events brought forth. She was trained in massage therapy and could see the hesitation in my movements. Discussing my ailments was only something I shared with people I trusted dearly and whom I knew trusted me in return with their cares and woes. At the time, I could not afford medical insurance and was not at the point in life where I trusted alternative therapies. A good anesthetic would do nicely. A few beers or some

rum and coke was just fine. I told her how it alleviated the pain, but how the mornings were rough anyway. I always woke up stiff and sore regardless of a drink or two but that movement and exercise seemed to help.

After a week of tumultuous weather we decided to try an experiment. I was regulating moderate activity in-between my work shifts. One night, she suggested the heat from her body would help during the cold damp nights. She was right. In the morning I woke up with less pain. A brief massage helped me regain my activity level faster than my normal stretching activities. Racheal Carr in *Arthritis: Relief Beyond Drugs* makes mention of how movement similar to yogic activity can benefit individuals who suffer from arthritis without medications. These movements reminded me of exercises from my high school physical education class and needed no other name. My friend's kindness in the morning walked me through some of these exercises after waking with 'heat therapy' and a brief massage. Not having insurance or a primary care physician at the time, this was the best treatment and therapy I had experienced for Ankylosing Spondylitis and Chronic Pain Syndrome.

Knowing what I know now, a study by Beyerman, K, et al clearly shows the efficacy of heat therapy in patients with osteoarthritis (*Efficacy of treating low back pain and dysfunction secondary to osteoarthritis: chiropractic care compared with moist heat alone*). It is not dissimilar to times I would go to a spa for massages or use the hot tub. Though for treatment purposes 'hot tub' is called a 'thermal bath.' My knowledge and experience with massage and heat treatment is backed up by a study in *Rheumatology International* by Ciprian, L., et al entitled *The effects of combined spa therapy and*

*rehabilitation on patients with ankylosing spondylitis being treated with TNF inhibitors.*

The benefits of these therapies are very useful, similar to a TENS unit (Transcutaneous Electrical Nerve Stimulation System) where electric stimulation is used to relieve muscle tension around the stiff joints. They both assist to alleviate the pain associated with bone fusion. The massage and stretching also have their scientific significance. A case study on one patient showed vast improvement on all measurable outcomes (Chunco R). The study backs up what other studies suggest on pubmed, more attention should be paid to these treatments. Massage and stretching can better be defined as physical therapy. It can take many shapes and forms. Woodyard explores physical therapy in the form of yoga and its ability to increase an individual's quality of life in a 2011 meta-study. Other studies like Yan, et al. show the efficacy of Tai-Chi for pain and stiffness. Yet some of these alternative therapies are not covered by insurance.

I did not know these options were the most effective treatments or therapies for me in conjunction with or without pharmaceutical medications. It was only after my friend moved away and I was once again left to my own accord to cope with my illness I began to understand what needed to be done...

### **Beginning to Take Charge of AS & CPS:**

My friend moved away and my health progressively deteriorated. Life circumstances and fortune made a move to the metropolitan area of Vermont the 'best choice' for my living situation. Little did I know, at the time, that this seemingly unfortunate turn of events would probably be one of the most unique turning points in my life. You see the toll AS and

CPS took on my physical and mental health brought me to some pretty low places in life. There was no way around it. If I was to turn my life around, I needed to be in an area where transportation was not an issue, health care was available and jobs were easy to attain and get back and forth to. To my dismay, I lost my job before my healthcare providers and I could work through some of the intricacies of my symptoms. Brief examples would include: the inability to stand or sit for prolonged periods of time, the fatigue which sets in over the course of a day, fighting to hide the pain, and the irritability that can come with those two. Solving this issue became my fulltime job as no employers in the area would hire me. I was over educated or not specifically qualified for the job. Temp agencies and dishwashing held me over until my unemployment ran out and my fight for disability succeeded after two failed attempts, though all my paperwork was in order. I needed to hire a lawyer to 'legitimize' my claim.

To this day, I still struggle balancing the time necessary to fit in the physical therapy that is needed, the tasks necessary to take the medications and eat a 'proper diet.' This is no small task. Managing AS and CPS symptoms are a full time job on top of any other activities an individual partakes in. There is no doubt about it and not many realize the struggle it takes to keep the symptoms subdued through the course of a day. I am reminded of one who did know by a note I found written to me. It was by an ex-girlfriend who I moved to Vermont with. I came across it on a recent trip back home cleaning out some of my old things. It is written in the book, *The Language of Positive Thinking: A Blue Mountain Arts ® Collection*. It reads, "Jarett, I hope this book gives you encouraging words to continue your 'new' positive outlook on life. –Love Always,

Jessica (a pseudonym)”. One of my favorite quotes in the book, “The greater the difficulty, the greater the glory.” –Cicero

Failing to get a reasonable accommodation from a specific job was just one of my trials moving to the Burlington area. It was odd that my request for a stool to sit during slow periods of time with my medical condition was denied, but a coworker’s was granted when she became pregnant. The invisible nature of my affliction often puts me in situations where I have to explain the intricacies of my medical condition repeatedly where others simply ‘get a pass.’ The clinical saying, “You never know what is going on with someone else.” comes to mind often during these exchanges. Looking ‘young and healthy’ has its advantages, but also makes me seem like a liar when I have a diagnosed medical condition people cannot see. When I am in physical discomfort and asked to perform a task that will increase my pain there is an extreme awkwardness involved when saying, “No.”

Working with my medical and care providers concerning this aspect of AS and CPS became a priority. When no jobs would hire me I turned to volunteer service for active engagement in the community. Here I was able to be upfront about my medical condition and the tasks I could and could not perform. The problem with this... volunteer service does not put food on the table or pay your bills. It was nice to have a sense of belonging and become civically engaged again as in my youth, but I needed more from this transitional period in my life. How could I prove to myself and others I am not just a statistic or a disabled individual suffering from Ankylosing Spondylitis and Chronic Pain Syndrome? What more could I do to take charge and take back my life?

No greater struggle in my life has there been than overcoming the negative coping mechanisms of my past from both AS and CPS. Triumphant over co-occurring concerns my ailment can manifest is not easy. Utilizing skill based therapies to retraining my brain over the quick relief some medications promise is no small feat. The glory from these struggles have come through the Love, Care and Support of individuals past, present and those I know are yet to come into my life. I have succeeded in moving from coping to managing to living joyfully day in and day out with my affliction. Without the struggles of my past, I would not have been able to manage my relationships with my care providers to get to the point where I know what works best for me at certain times of the year over others. I would not know when I need to reach out for more support from my community members and loved ones. It would not be possible for me to be writing a thesis in eSPN format telling my story about the trials and triumphs over AS and CPS through the balance in perpetuated medicine and holistic therapies.

### **Balance Understanding My Aliment's Role in Life**

“I am not bound to win, but I am bound to be true. I am not bound to succeed, but I am bound to live up to the light I have.” – Abraham Lincoln

For me, every day is a triumph. I may struggle with stiffness, soreness and pain, but I get out of bed knowing that my life has meaning and purpose. I find this understanding hard to accept sometimes, but realize my writing and master's degree have assisted with this realization. Knowing AS & CPS's role in my life has not been easy. I want more from my life than a sedentary lifestyle or one where I simply give my time to others.

Volunteering for many different organizations in the Burlington area allowed me the opportunity to apply my skills in a new way. I could be active with group collaboration working toward a common goal. Before applying for graduate school there was one walk for arthritis in the area I assisted with. There have been none since. Similarly, there are no specific support groups for individuals suffering from AS or CPS. An online community, KickAS.org, does exist with some helpful information. During the period of time right before graduate school, I went through many different medications and therapy routines with my medical professionals and care providers. I still looked for employment. Nothing seemed to work.

A correlation between the time of year and my pain intensity would not be acknowledged until recent years. Back then we were fighting with medication doses and frequency of physical therapy visits. I had to specifically ask for an appointment with a nutrition expert years before this type of service became popular. Some medications were too strong, others too weak. Some needed another medication to counteract the negative effects of another. Before I knew it I was on what is called, “A Medication Train”, or technically “polypharmacy.” I am still fighting to reduce the medications I am on and reduce the dosage of others because of the potential side effects. The life I live can be like a pendulum swinging from ok days to severe days where I cannot move. Sometimes the medications I am on help. Other days they seem to be ineffective at best.

Balance is the key to moderating the transitional periods that would otherwise be severe making them moderate, allowing me to engage in service activities. My doctors know the medications I am on have their limitations. Together we see alternative medications and

treatments might be the ‘best’ route for long term care. The trick at this juncture is finding the right balance. It is a struggle to know there are medications that work, but their effects in the long run are destructive. Complimenting them with nutrition and movement therapies can alleviate their necessity. The pain relievers are addictive and devastating to the human body, even when used as directed. I have been told by doctors that repeated use of corticosteroid injections (more than three to four times a year) can actually weaken bone structure and cause other serious health concerns. Medical science is just now acknowledging the benefits of holistic medications which allow the reduction of opiate use for chronic pain. Lucas’ 2012 study, *Cannabis as an adjunct to or substitute for opiates in the treatment of chronic pain* has been backed up with recent studies implying additional therapeutic paradigms, including addiction recovery. A holistic balance between perpetuated medicine and alternative treatments has been instrumental in allowing me to move my life forward. It did not come without many sacrifices though.

After a debate that lasted over nine months with my son’s mother, I knew I needed to literally and figuratively get my life back into motion. You see she did not feel fit to raise our son. Nor did she feel I was capable, as a disabled individual, to ‘properly’ raise a child. It was out of love and care that a decision was made to give our child up for adoption to an infertile couple, but some of the things said relating to AS and CPS left me feeling like less of a person, incapable of performing the simplest of tasks. It was then I decided to take matters into my own hands to prove to myself my disability was just an aspect of my being, not the entirety of my essence.

My service to the community and involvement with local organizations assisted me in attaining what I never thought possible, entry into a master's degree program. I had the support of my medical professionals, care providers and my son's mother behind me. The support services at the University of Vermont assisted me in my comfort level returning to school. I had all that I needed to be 'successful' in my educational endeavor. This is how I began to make sense of AS and CPS's role in my life. I did not realize that studying subjects like *Human Rights and Disability Advocacy*, *Beyond Medical Models*, and *Happiness, Mindfulness and Health Benefit Outcomes* would mean so much not only to myself, but others in my life. I learned the importance of alternative medical paradigms and the struggles of individuals thriving through other ailments.

What does it mean to be a disabled student at the University of Vermont? I have been asked this many times. In addition, I was asked to speak on a panel for the 2014 Disability Awareness Month. Unfortunately, I was unable to attend it. Instead, I will write my feelings toward this matter here. Like the back and forth that is AS and CPS, being a disabled student like myself has its advantages and disadvantages. I feel privileged and disadvantaged at the same time.

When I park my car on campus, I have the choice of any spot I want with my orange handicap placard. But I also have the thoughts in the back of my head, "Who is watching me, a young healthy looking individual, get out of this vehicle." carrying a backpack while I wince in pain. I have had notes placed on my car stating, "You shouldn't park here." Though I have all the documentation and paper work that allows me the support services I need, it still does not remove the stigma and social inequality that goes along

with being disabled. Walking around campus I can feel like I do not ‘fit in’ with all the other students. I try to hide my pain to look and seem like ‘the average’ or ‘normal’ individual. In the back of my mind, I am always worried someone will ‘find me out’ or that I am actually in pain or ‘faking’ the smile on my face. Worst yet, I fear the lack of a smile on my face will deter individuals from seeking my assistance or advice... This is also how it can feel going into a job interview. It is hard to ‘be yourself’ when trying to ‘hide’ the fact you are in pain. Most interviewers see there is something ‘wrong’ or that I am ‘hiding something’ and pass over me for the position.

Being an active member of Active Minds through my UVM career has helped remove some of these ‘fears.’ As a club that strives to reduce stigma associated with physical and mental health concerns of all kinds, especially suicide prevention, my involvement has taught me a lot concerning the how’s and why’s associated with stigmas in general. For the most part, stigma starts with learned behaviors from society and therefore it is up to an individual to stop them. Like all things, this can only come from practice and exposure. If there is one thing AS and CPS have given me it is a lot of practice and exposure to reducing stigma and fears of all kinds in my life.

Striving to assist myself and other students on a higher scale, a year into my graduate program, I became involved with the Graduate Student Senate. Here I informed the graduate body of volunteer opportunities throughout the Burlington area helping to bridge the gap between the two communities. Attending meetings on a regular basis illustrated the interworking of the graduate college and the University in general. It allowed me to understand the importance of my work as a student looking at the big

picture on campus. My outreach and involvement earned me the award, “Graduate Senator of the Year, 2013-14.”

I had an epiphany working with these campus organizations. They showed me that reading books and writing SPN’s concerning AS and CPS on *Anatomy of an Illness*, *Spontaneous Happiness*, *A Matter of Dignity* and many other books and articles actually made me an expert on the subjects of AS, CPS, my narrative, my life and my educational process. UVM and my journey to and through the Interdisciplinary Program brought meaning back into my life. Class and the knowledge gained inside and outside the classroom become a meaning making center. It allowed me to explore feelings and notions behind violence, disability, marginalization, ‘cycles in chronic pain’ and inflammation in my body. The connections I was building with my peers and the knowledge gained from my education was becoming wisdom. Battling chronic pain most of my life and striving for a degree of ‘normalcy’, UVM showed me as Frankl wrote, “...meaning can be found not only in work, but also in love.” (Man’s Search for Meaning, P.145) I began to learn how to love again. I found it possible to love myself and others more and move past perceived wrongs. I could put away my pain and move forward with my life aspirations.

With my new found wisdom, I know I can write for the marginalized, the disenfranchised, disabled, underemployed, unemployed, and be the voice of the victim and the oppressed... To anyone that thinks their voice or vote does not matter, I write this now, “It does, it really does matter.” The epiphany showed me that “I” no longer need to fear the ‘Dragon of Chronic Pain’ within. The ‘monsters’ and ‘demons’ from

my past can be left behind. In moments when I least expect to be in charge of my pain, illness or life situation, I remember a presentation I gave at the Student Research Conference at UVM, April 16<sup>th</sup>, 2014. My topic was similar to this thesis in bridging the gap between perpetuated medicine and holistic therapies. One of my points stated arthritic lower back pain is leading the nation in claims for social security disability payments (spondylitis.org, Social Security).

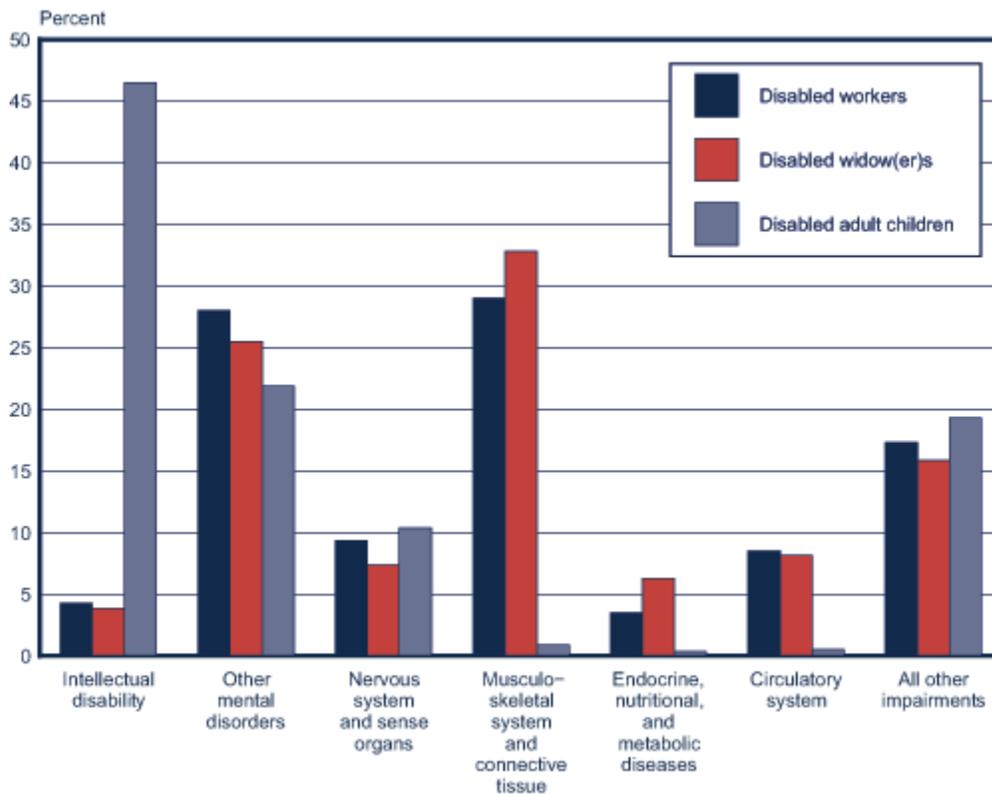


Figure Via SSA.gov

U.S. Social Security Administration, Office of Retirement and Disability Policy

As you can see from Social Security’s 2011 payment status, musculoskeletal and connective tissue concerns were the leading cause of payments among disabled workers and widow(er)s. I presented on “Invisible Disability” issues and wellness October 23<sup>rd</sup>,

2013 at the University of Vermont's Living Well Studio as well. The focus was on bringing a 'better' system of wellbeing to individuals who have similar concerns as I, including addiction recovery journeys and mental health concerns. Presenting on a system more inclusive of a better quality of life is also supported by polls suggesting more than 70% of working age individuals with a disability would rather have meaningful work than government support (respectabilityusa.com). If individuals such as myself find the right balance or are trained to seek it out earlier in life with medications, skills and holistic therapies, meaningful work is easier to find. Sitting in silence I have time to contemplate about my role towards the marginalized, unemployed, and disabled of all kinds. I know my life has meaning and so does theirs. It is never too late for a fresh beginning for anyone. Society should be more supportive of these efforts and the educational process toward this end should begin earlier. AS and CPS have shown me there is a need for people to see individuals rise above systems of constraint and life circumstances. Collective strength will always come from individual responsibility and we all have an individual responsibility to others.

I can still struggle with the true nature of 'pain' and accepting Ankylosing Spondylitis as a permanent disability. When I received my forms to review my disability claim, I struggled with the language in the letter: "...to make sure you continue to be disabled." Of course I am! The illness is chronic and degenerative. There is no cure. The letter really seemed like a joke played on me by the sender. Aren't all the doctors' appointments I go to and the pills I take enough evidence that there is something 'wrong with me'? Trust in my care providers and my educational process is what keeps me going day in and day out

at this juncture. I have seen that kindness, faith and loyalty win out over suffering, doubt and mistrust. My care providers know I am more than a case number or a statistic, unfortunately the government hasn't caught on yet in how it manages 'care.' I must write for my health and wellbeing while mentoring and educating others through my story incorporating perpetuated medicine with holistic therapies and its balance. Every person deserves to be educated properly. They also deserve the 'correct' treatment covered by their healthcare.

I know the importance of getting this information into the hands of educators, parents, policy makers and medical providers of all kinds for one simple reason, I see signs and symptoms present in my son I experienced at his age. Even now at four years old he is having difficulty falling asleep. His adoptive parents are giving him a natural sleep aid, Melatonin, to assist with his bed time. He is active and cannot sit still as I was at his age. Though he is not expressing or experiencing 'growing pains' at this juncture, the fact remains, warning signs for ailments of all kinds can be recognized earlier in life preparing individuals for the life ahead of them.

My son's adoptive parents are in a unique position to be able to ask questions that arise in my son's upbringing which I was not afforded. They have access to doctors that understand the intricacies of rheumatologic disorders, juvenile arthritis and other conditions that can arise in early childhood development. They can ask the birth parents about their childhood, how situations were handled and ask questions of experts concerning the best course of action, should symptoms arise. The same is true for ailments of all kinds, not just for them, but all educators, parents, policy makers and

medical providers of all kinds. This is an opportunity in educational policy to look for underlying causes behind symptoms and prepare individuals for the resilience it takes to manage or overcome the obstacles they present without simply ‘putting a band aid on the flesh wound.’ The more information available, the better understanding we can use for policies concerning our children’s education, upbringing, wellbeing and quality of life. Incorporating the knowledge of holistic education and skill based therapies can complement current curriculum and policies.

#### **Chapter 4: Navigating the Real Life Implications of Chronic Disease**

##### **Medication and Therapy Management:**

Time with my son and his adoptive parents continues to illustrate the importance of fostering relations between educators, policy makers and medical providers. Both of them are in the Vermont Educational System, one as a teacher, the other as an administrator. My own parents have been in the New York Educational System for well over forty years. Seeing the similarities in how each system works in tangent proves how easy balancing policies concerning perpetuated medicine and holistic therapies could actually be. Policy would need to come from above, not just taught at the local level from some parents and educators. Knowing there is a time and place for medications is paramount, but should come in conjunction with other therapies or when those therapies are ineffective.

In my own life, I have seen the effects of using medications alone without alternative treatments. The results are not as effective as when used in conjunction with holistic therapies. Likewise, when I did not have access to medical treatment or refused to take

the advice of my medical providers, the effects on my wellbeing were devastating. For me the balance between the two is clear. When used together, quality of life is increased and daily functionality is improved. No better time was this illustrated than a year into my graduate studies and can be used as a universal example bridging the gap in perpetuated medicine and holistic therapies for anyone in life.

I was taking nine credits in the fall and spring semester, working with my medical and care providers and working a regular schedule of physical therapy with holistic tinctures and teas. My courses and classwork were going well in addition to my volunteer service. I was involved with group mindful meditation practice four to five times a week and participating in group yoga two to three times a week. This mixed with a nutritious diet I found on “kickas.org” helped keep me balanced in my wellbeing and quality of life. Aquatic therapy at the local YMCA pool was also helpful. I found this was a great combination and balance between the ‘prescriptions’ and the holistic treatments.

This type of ‘lifestyle’ is not without its pitfalls though. It requires access and the willpower to follow through. Without healthcare it would not be possible to attend the regular schedule of doctors’ appointments necessary to monitor my illness. It would also not be possible to manage the medications to figure out what works and what does not. In addition, access to trained physical therapists to teach you what you need to do on your own would not be possible. Luckily, as a student I have access to affordable yoga classes and free meditation sessions. The majority of healthcare plans do not cover these services. Some will as long as they are ‘billed as different therapies.’ Meditation would have to be covered in a cognitive behavior therapy session or group. I attended one

weekly for five years and ended up leading the meditation sessions. Likewise, in my research I found some plans accept yoga as a treatment, but it is billed as physical therapy or as part of cognitive behavior therapy for mood disorders. In addition, going to see a Naturopath is not covered by Medicare or Medicaid though they are recognized as medical professionals. This can put individuals at a disadvantage if the prescription medications are ineffective or they wish to seek holistic therapies.

Fortunately, in the State of Vermont there are places like The Vermont Center for Integrative Herbalism (VCIH) and Vermont Center for Integrative Therapies (VCIT) which offer these services at affordable cost, no cost or a sliding scale fee. The VCIH allows you to pay for your initial consultations by sliding scale fee or by volunteering your time to the Onion River Exchange, a local program where you exchange time for products and services. This is also how I pay for my herbal teas and tinctures as their services are not covered by any healthcare plan. The VCIT does accept sliding scale fees, Medicare patients, or refers individuals out after an initial consultation. Their services are centered on yogic activities for mental and physical wellbeing. I bring both of these services up as examples of the type of treatments individuals should be informed and educated about earlier in life.

In addition, the VCIT services are not dissimilar to programs already being offered in school systems around the country. A good example would be UVM's Mind Body Wellness Program which offers meditation programs of all kinds for students as well as mindful movement activities for mental and physical wellbeing. The program is preventative in nature. It assists students prepare against stress reactivity and thereby

increases their resilience towards illness and ailments of all kinds The study, *Randomized controlled trial of mindfulness meditation for generalized anxiety disorder: effects on anxiety and stress reactivity* gives an example of the outcomes of such activities. Other therapies have a longevity of successful outcomes including Jon Kabot-Zinn's Mind Mody Stress Reduction Program, briefly outlined in *Full Catastrophe Living*. An example already in place at the high school level would be Transcendental Meditation brought to New Horizons, New Haven by the David Lynch Foundation. Principal Maureen Bransfield was quoted in the New Haven Independent as saying, "The school is calmer and quieter. In surveys, the school's meditating students report that they now fight and argue less, accomplish more, and feel happier and less stressed." (MacMillan) These are just some of the benefit outcomes of incorporating holistic therapies in the educational process earlier in life.

I will be honest. I have not found, nor do I believe, there is one 'perfect' model to incorporate holistic education or skill based therapies earlier in life. I do believe there is value in incorporating them. There were times intentional stretching worked better for me or aquatic therapy. Other times intentional reading or walking worked for my wellbeing. For students and individuals of all ages, choice in focused activity is the key. I found Sonja Lyubmirsky's pie chart in *The How of Happiness* to be helpful in describing the potential outcomes (Page 19). From research in multiple fields of study our wellbeing can be described as being fifty percent fixed, ten percent circumstantial, and forty percent based on focused or intentional activity. Some studies suggest the percentages vary, but the premise is sound. Creating educational policy and curriculum, with student choice of

participation, that incorporates intentional focused activities will benefit future generations.

What would this curriculum or policy look like? I will not pretend to have all the answers. As stated, programming will look different everywhere. It's the outcomes that are important. I will give a brief example of what it 'could' look like. The first aspect of this policy would be to evaluate the feasibility of a 'nutritious affordable meals for all' program. This would allow all students the opportunity to have two meals at school instead of one. It may be possible to implement five minutes of focused reflection after 'morning announcements' where students quietly reflect on what they have to do that day, write a to do list or just sit quietly. Depending on the age group, a set time during the day would be evaluated for focused attention alternatives should the student wish to participate. If a student in high school has a 'free period' alternatives should be explored that peak their interest and allow them to participate. Likewise, physical education curriculum can implement focused attention in all its activities by encouraging students to engage in the activity with intent. I know for me there were times we were told just to run around in a circle for ten minutes. Had we been told to focus on our stride and count as we inhaled and exhaled there would have been the intentional focus and benefits that come with mindful activity. In addition, class offerings on the basics of skill based therapies can be offered at the undergraduate level. These are just some of many recommendations.

### **Societal Influences Toward Medicine**

On a recent trip to Florida to visit my family, I had time to reflect back on what influenced me in my choices for treatment and therapies over the years. It became very clear to me through interactions and conversations that societal influences had a direct impact on my choices. When something went ‘wrong’ in my life, I took the advice of medical professionals. I had been programmed from an early age to put my faith and trust in them to ‘find the correct answers.’ If I broke a bone, I trusted them to properly ‘fix’ it. If I needed stitches, I trusted they would properly suture the wound to minimize scarring. When I became ill, it was assumed the treatments and pills were what was ‘best’ for me. In some cases, I was not informed of the long term side effects of starting medications in the first place or informed of alternative treatments.

These societal influences are similar to peer pressure. The pills have been pressed upon society from an early age. I was led to believe what the doctors said was law. Even the medical training, until recent years, has socialized these influences into their curriculum. The doctors always have a ‘better pill’ when treatments do not work. The “Better Pill Syndrome” can be like peer pressure. This influence is similar to a ‘rite of passage’ pressed upon individuals turning twenty-one or at a high school or college party to drink alcohol. Individuals can feel they have no choice but to consume what they are given. Often, no other options are provided.

During my classes *Human Rights and Disability Advocacy* and *Beyond Medical Models*, I became curious where this influence stemmed from. Over a hundred years ago, Abraham Flexnor did both a service and a disservice to medical education. Though he

‘standardized’ what a ‘medical school’ should look like, the resulting exclusion of women from admission and resulting laws banning holistic health as healing models narrowed the focus of what healing paradigms look like to present day. It would take two generations, women’s suffrage and the civil rights movement to begin to sift through the ‘standardization’ the Flexnor Report brought (Stahnisch & Verhoef). In fact, the three thousand year old practice of acupuncture was not recognized by the National Institutes of Health as an effective therapy in the United States until 1997.

Most of the doctors I saw were of an older generation of medical training. When AS was finally diagnosed, this generation of doctors did not offer me alternatives to medications. After years of being prescribed narcotics I realized what a racket the pharmaceutical companies have when dealing with chronic illnesses. If holistic treatments and skill based therapies are not taught early in life, individuals may never know about them. Like an addict, they will stay hooked on the lie some in perpetuated medicine feed them. I had to research each prescription medication I was given to find out if they were ‘necessary’ for my medical condition. Perhaps, there was an alternative form of treatment.

If I truly want to live a ‘high quality of life’, I need to consider all aspects of AS, CPS and my desires for any future work I engage in. I need to understand the ups and downs my symptoms create within the ‘normalities’ of daily life. There are not many opportunities in this world where one has the access and the freedom to attend multiple doctors’ appointments a month, work a high skilled and paying job while living on their own. For some in my situation, this seems like an impossible feat. I take strength knowing the world is slowly changing. It is for these reasons I put this thesis in the hands

of educators, parents, policy makers and medical providers of all kinds. Bridging the gaps in communication for our children and the future is everyone's responsibility.

With the current lack of progress in pain management treatments it only makes sense to incorporate holistic treatments and skill based therapies earlier in the educational process. As a society and culture change has to begin with our educators and parents. Skills should be taught over pushing pills for any ailment or condition. With holistic educational programming and skill based training in our grade schools and high schools we give our children the best chance of living the highest quality of life possible. Should they come down with an illness or long lasting ailment they will be better prepared to handle the 'adult' roller coaster of life that awaits them sooner than their peers.

Even if they choose or have to find a balance with medications, they will be better off in the long run and suffer less side effects. More importantly, the societal influence will shift from a 'quick fix', pill popping, myopic based one to a resilient, skill-based, broad-minded, mutually supportive one. As life expectancy increases, so should our expectations for the upcoming generation's productivity, quality of life and communal functionality. This will only happen by continuing to bridge the gap between perpetuated medicine and holistic therapies.

### **Conclusion**

In concluding my SPN thesis, I would like to reiterate certain themes and points. Through the course of my Master's Program and research I learned that supportive environments

and communities can assist anyone in making progress in life by moving from coping to managing any situation or circumstance (be it ‘illness’ or a ‘normal’ walk in life). This can be enhanced through societal support for earlier educational programming to assist individual development of skill sets to manage stress reactivity and chronic ailments. Resiliency training has health benefit outcomes regardless of one’s physical or mental health. Though these programs may look different throughout the country, the goals are the same. They will lead to a more productive, more informed, better educated society and workforce. This can be achieved by bringing skill-based therapies together with perpetuated medical models to benefit treatment and diagnosis earlier in life and in the educational process.

Medical educational paradigms are catching up by incorporating alternative and holistic therapies, but grade school, high school and societal structures are still lagging behind. Incorporating skill-based and holistic therapies also have a cost benefit associated with them as they can easily be taught in school, practiced at home and have a low cost to insurance companies. As we move forward as a society it is important to always look to the truth in what we are unfamiliar with to see the similarities with what we already know. This is where commonality and compromise can be found for ‘the greater good’ of all. When we look to the underlying cause and not just the symptoms it is advantageous to create better educational policy through collaboration for our children’s education, upbringing, wellbeing and quality of life.

With Sincere Respect and Gratitude,

Jarett Chizick

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