

*Peace be to earth and to airy space
 Peace be to heaven, peace to the waters
 Peace to the plant and peace to the trees!
 May all the powers grant to me peace!
 By this invocation of peace may peace be diffused!
 By this invocation of peace may peace bring peace!
 With this peace the dreadful I now appease,
 With this peace the cruel I now appease,
 With this peace all evil I now appease,
 So that peace may prevail, happiness prevail!
 May everything for us be peaceful!*
 [Atharva Veda XIX] Vedic poem taken *From Earth Prayers from Around the World*

Good evening, ladies and gentlemen. Thank you, Nesrin Shaheen, and the Anti-NMDA Receptor Encephalitis Foundation, for allowing me to share my thoughts with you tonight.

My name is Linda Nourse, and I am the mother of David Clarke, a young man currently battling Anti-NMDA Receptor Encephalitis. Anti-NMDA Receptor Encephalitis is a brutal, life-threatening disease and recovery, when it occurs, is measured not in weeks or months, but in years. For those of you who are not familiar with this disease, here's an excerpt from the Foundation's website. **And I quote**

Anti-NMDA receptor encephalitis is a disease occurring when antibodies produced by the body's own immune system attack NMDA receptors in the brain. NMDA receptors are proteins that control electrical impulses in the brain. Their functions are critical for judgement, perception of reality, human interaction, the formation and retrieval of memory, and the control of unconscious activities (such as breathing, swallowing, etc), also known as autonomic functions. In anti-NMDA receptor encephalitis antibodies are generated against NMDA receptors and go on to attack these receptors where they are found in their highest concentration: within the brain. The reasons why anti-NMDA receptor antibodies are formed is not yet fully understood. - **UNQUOTE**

My son, David, is smart, funny, impulsive, sensitive, fiercely loyal to the people he loves. As a small child, he was mischievous and extremely nosy – that little boy just loved to be in everybody's business! Growing up, he tended to be attracted to the "naughty" kids and was no stranger to the Principal's office. As an adult, though, he's become more responsible. He's married and the father of two

small children, works full time, is extremely active in his church, and was well on his way to starting his own business as a chef and caterer. Yet he still tries to project a tough image. Only problem is, his heart, as the saying goes, is as big as all outdoors. David is the first one to mediate or apologize when there's conflict. He hates any kind of injustice and will do all in his power to help or defend a family member or friend – up to and including giving up the coat right off his back, as I learned recently from a friend of his.

David was diagnosed at St. Mary's Hospital in Montreal in June 2014, at the age of 29, and was subsequently admitted to the Montreal Neurological Institute & Hospital where he remains to this day. At the time, his son, David Jr., had just turned 6 years old the month before. His daughter, Daniella, had yet to celebrate her 4th birthday. David is now 31 years old; David Jr. (or DJ, as we call him) is 7, and Daniella is 5. I say all this because I've become obsessed with marking the passage of time! At first, my greatest fear was that I might have to bury one of my children – a parent's ultimate nightmare. Then I was anxiously impatient for noticeable improvement. Now, a year and a half later, I worry more about how much catching up my son will have to do when he recovers. And, thankfully, he is showing signs of recovery.

David received the same treatments that some of you are all too familiar with including IVIG (also known as immunoglobulin therapy), Rituximab (a drug used to treat autoimmune disorders and certain types of cancers), MRIs, countless EEGs, and, when there was no progress after a year, Cyclophosphamide. Although he is still completely bedridden and has yet to regain full consciousness, my son does have longer and longer periods of clarity each day. At these times his gaze is focused and he responds appropriately to verbal stimuli. He can sometimes obey simple commands and, from time to time, he is even able to say short (not always polite) words, sometimes even without the aid of a speaker valve on his tracheostomy.

Ladies and gentlemen, there are too many Davids out there! Some white, some black or brown, some previously healthy, some not. Some older than he is; some much, much younger. I'm here tonight for two reasons. One – By speaking to you about my David, I wish to bring to your attention the fact that there are way too many families wondering how this terrible thing could have happened to their loved one. So far as anyone knows, this illness is not a result of anything the person did or didn't do, it has nothing to do with his or her medical history or lifestyle, it doesn't seem to be genetic ... so what IS it? The only way to find the answers we so desperately need is through Research. If we can find the Cause, surely we can find the Cure?

I'm also here to honour the people who are suffering with this cruel disease, either as patients, family and friends of patients, or as caregivers. This experience has been, for me, the single most profound wake-up call ever! Of course, we're all aware of and sympathetic towards people who are afflicted with any life-threatening illness and the effect it has on the people closest to them. But there's nothing like first-hand experience to take a person beyond sympathy or even empathy, and straight to awe.

Because dealing with a devastating illness requires each of us to find a strength we never knew we had, never would have dreamed we'd need. And we DO find that strength, don't we? We deal with the worry, guilt, and helplessness. We deal with watching our loved one wracked with uncontrollable movements, seizures, confusion, erratic behaviour, coma, and more. We deal with seeing someone we love attached to all kinds of tubes, unable to communicate or perform even the most basic tasks for themselves. We deal with the Fear of an uncertain future. Many have had to deal with relapses. Some have had to deal with saying goodbye.

Friends ask how I'm holding up under the strain. My answer is this: I watch my daughter-in-law, Melissa, decorate David's hospital room for every occasion. She celebrates every single birthday, anniversary, and holiday with him as if he is aware and participating with her. I saw my daughter, Shana, leave her life in the U.S. to come home and be with her brother. I see my other son, MacAndrew (David's fraternal twin), travel back and forth from Gatineau to Montreal to show his love and support for his brother and for the rest of our family. Mac and his lovely fiancée, Sandrine, are here with me tonight. Members of David's church choir come to the hospital to sing for him. Friends, co-workers, even acquaintances have all, in one way or another, demonstrated their love and concern. These actions, and many others that I could mention, not only give me Courage, they have awakened in me a higher level of Patience, Compassion, Endurance, and Humility than I would have thought possible. By forcing me to seek Balance, Harmony, and Peace in order to cope, the illness currently affecting David has strengthened my heart and instilled Tolerance for a situation which could otherwise be overwhelming. Here I'd like you to notice that I said "*the illness currently affecting David*" – not "David's illness"! On his behalf (and especially my own), I reject and refuse to "own" this illness. It is a temporary detour to my son's physical and spiritual path; a powerful experience for learning and growth for him and everyone close to him.

Yes, dealing with ANMDARE is incredibly painful. But, even in this, there's room for gratitude. I'm grateful that David was diagnosed early and correctly

because this illness is often misdiagnosed. I'm grateful to the doctors, nurses, and medical staff working tirelessly to return David whole to his family and friends. I'm taking full advantage of the opportunity to kiss him, hold his hand, and stroke his forehead as much as I want – without having to hear, “aw, c'mon, Ma!” Although, in truth, I really wouldn't mind hearing that now.

I'm grateful to the survivors and families who bravely share their stories, concerns, and victories on Facebook, reminding me that I'm not alone.

And I'm grateful to this organization. There's a line in one of my favourite movies – *Sneakers* – that goes “Information is Power.” The ANMDARE Foundation provides encouragement and support, yes. But they also provide Information and, by doing so, they demystify to a great extent, this terrifying disease.

To those individuals who are now suffering with or in recovery from ANMDARE, I offer sincere prayers for your complete and permanent recovery. To your families I offer my most heartfelt respect – and my promise to support you and this Organization to the best of my ability. I pray for the comfort of all those who are mourning a loved one – I won't say “lost” because your loved one is with you always. Death is not a victory; the Victory is in our ability to go on with Dignity, blessing and cherishing the memory of our loved one by recognizing and honouring the Divinity in all Life; by treating ourselves with tender regard and respect for our own health and safety so that we may live to Serve others in need.

To everyone here tonight, I thank you for your presence here and for your attention. I humbly thank you for your support for this Foundation and, by extension, my son David.

On his behalf and mine, I wish you ALL ... *Peace*.
Thank you.