

The Transition from the Facebook Town Hall to compassionate learning; By: Gene Desotell & Tabitha Orth

The concept of Facebook has been around a few years as a social Media site. The idea was started at Harvard University as a meeting place where students could connect with one another via the internet. Then Mark Zuckerberg brought it publically from Harvard to his own company.

It became an international social media site in the beginning. Then it began to transform from the Town Square, to Sales, Marketing, Business, meeting rooms, education, and almost any purpose where people would come together in public or private to discuss issues of interest.

The non-profit, International Autoimmune Encephalitis Society got its start in 2003 when Anji Fesler established a Facebook site to provide support to those with Hashimoto's encephalopathy. In fact, she named the group Hashimoto's encephalopathy. This was the first Facebook site to be established that invited discussion about what is referred to today as: Autoimmune Encephalitis. Facebook's social network became an ideal place for all types of illnesses to establish groups around a common topic. Facebook provided a platform that enabled people to create a community that provided support and interaction about their shared topic and experiences. However, Facebook was not the only meeting place at the time. In 2006 my wife had become ill with what would be later known as Autoimmune Encephalitis. I read a lot of medical studies on National Institutes of health and would relay what I read to those with the disease on yahoo Groups.

For years, people would come and go, to and from, this open site exchanging all kinds of information about Hashimoto's encephalopathy. Member's medical care was being overseen by a wide variety of different types of medical practitioners. Patients were being treated by Chiropractors, Endocrinologists (Thyroid doctors), Neurologists, Rheumatologist, General practitioners, dietitians and Holistic practitioners. People in the group would exchange what information they had learned from their medical practitioner about their illness and what treatments they were receiving. In those days, it was like a public square where members were exposed to all sorts of ideas and information from across the spectrum leaving them to decipher the accuracy of what they had learned from each person.

Anji Fesler's Facebook group grew and adjusted over the years as research about the disease was slowly being published. If I am remembering correctly, there were less than 100 studies published between 2003 to 2006. It was four years after the group was established that the first antibody in autoimmune encephalitis was identified, anti-NMDAr. At that time, Hashimoto's Encephalopathy was considered to be a 'type' of autoimmune encephalitis that was in a separate category than anti-NMDAr. The two disorders were thought to be more different from each other than they were thought to be more similar to each other. Over the years, Anji changed the name of her group to

better reflect what the research was saying about the illness, but the site address has always been the same.

Fast forward 12 years from 2003 to 2015. Anji Fesler's support group now boasted two volunteer administrators who worked alongside her, myself and Tabitha Andrews Orth. Research in the field of Autoimmune Encephalitis had taken a great leap forward and the past two years had resulted in more publications than the previous ten years combined! The disease was getting recognized and catching the interest of researchers in Neuroimmunology. It was now thought to be more common than originally hypothesized. In 2011 Dr. Dalmau and Dr. Lancaster published the largest study of 577 patients with anti-NMDAR following them over a two-year period. A treatment protocol that was established from this study was now being utilized as a guide for practitioners treating patients with all types of Autoimmune encephalitis. 2012 brought greater change and awareness through the New York Times Bestselling autobiography by Susannah Cahalan: *Brain on Fire my Month of Madness*.

In 2015 the emergence of Autoimmune Encephalitis as a new specialty in Neuroimmunology was taking hold. 13 antibodies had been identified (not including the 9 paraneoplastic antibodies), today we are at 16 last count. During 2014, with so much being learned about AE, we decided to begin to post research that answered a question a member asked in order to help people become aware of some of the new things that had been discovered about AE. This growth in discovery through research was an especially challenging time as the support group moved toward providing information that disproved other theories about these disorders and how to treat them. We three Administrators recognized that some of the information shared in our group was either out of date, disproved through new discovery or came from a source that was not peer reviewed or scientifically proven.

We became aware that this was not helping members and in some cases, advice taken had made some members sicker. While some people tried diets, we read that when a patient is suffering from these disorders or undergoing certain treatments, it may not have been the best time to go on a diet. That one needs to maintain strength and that the recommended diet suggested for it's ability to kill the attacking antibodies, actually did no such thing. Some examples of member suggestions were that Turmeric and Curcumin could control the antibodies attacking the brain. There was even responsible looking research on it but was later determined to be someone selling the products. Once again, the information lacked concrete evidence on the national institutes for health in the research. One member had been taking 6mg of prednisone daily for ten years by the doctor treating her. She trusted her doctor but recognized her condition was gradually worsening. New research recommended 60-80mg daily orally or 3-5 days of 1 gram IV steroids. The dose of 6mg daily would not control the antibodies attack of the brain. Research from Mayo explained that patients should not be on Prednisone for long lengths of time specifying 9 months in some research with other courses recommended based on the individual patient's presentation. Many members were being undertreated as Autoimmune Encephalitis was a new disease and it was not yet being taught in Medical school. Many doctors had never heard of the disease and were therefore unfamiliar with how to diagnose or how to treat it. It was even more under recognized then as to now.

It became clear that increased awareness about these disorders needed to occur throughout the medical community and psychiatric community. Group members needed to become strong self-advocates and learn what they could about the disease in order to get full neurological work ups that would lead to an accurate diagnosis and treatment plan for best outcomes. This goal for members was a tall order. Due to their symptoms, they could not read and understand the advanced research. Had short term memory issues and other cognitive challenges and had no medical training. Administrators of all of the Facebook groups that had been established had no medical training. Most, like Anji Fesler, began their group because they were a patient or a family member of a patient. This was the case with our group as well.

The three of us began to assess the current challenges: How do spread awareness among the medical community? How can we share only accurate information through evidence based research with our members? If education is power, how can we help members learn about Autoimmune Encephalitis in an easy user-friendly way? How can we prevent members from sharing information that is not accurate or that could cause harm? How do we create an environment that leads to an accurate diagnosis, aggressive treatment plan and best outcomes for our members?

Considering all of these factors, it became clear to us since we had spent a great deal of time reading the published work of the leading researchers in the field such as Drs. Dalmau, Irani, Mckeon, Lancaster, Vincent, Graus, Titulaer and Pittock for example, that many members were misdiagnosed, underdiagnosed, and receiving treatments which would either not be effective for Autoimmune Encephalitis or in some cases had shown to be harmful to the individual.

We began evaluating how we could change our mission in the Facebook environment to better assist our members by directing them to competent help that would lead them to a treatment plan best suited to their health needs. We decided that the focus of the group should shift from that of solely providing emotional support to one with a strong focus on education. A gradual instruction-based educational support group focusing on recent research in the field. While providing emotional support, we recognized that fear of the unknown can be very scary for the person who is facing illness as well as for their family members or friends. That if a person could have a better understanding of their illness, they would feel in more control and play a more active role in their medical care. Our motto: "Empowerment through Education" was born. People could better evaluate information for accuracy. We found that members who became better informed would receive treatment earlier, and treatment consistent with the experts at Mayo, Oxford, Hopkins, and U of Pennsylvania.

Our website serves the entire Autoimmune Encephalitis community including medical professionals and medical students. As a courtesy, we provide a Doctor's List comprised of physicians who have published peer reviewed research in the field of Autoimmune Encephalitis confirming they hold a level of expertise that will best serve

the patient in need. In September 2016, we incorporated and became a non-profit organization. We are proud of the medical experts that are on our Board of Directors and those who act as Expert Consultants. We are grateful for their guidance and willingness to answer questions we have on behalf of best practices for our members.

While our approach to moderating the IAES support group was a new concept to people who frequently joined groups on Facebook and expected the usual town hall type of forum, we appreciated their willingness to change, adapt and participate in the spirit of our goals. That every person who suffers from Autoimmune Encephalitis see an expert in the field and reach best outcomes. We appreciated that during the time of our transitioning the support group to its new mission and focus back in early 2015, that some members mourned the time when emotional support was the sole function of the group. Some Administrators of other groups in the AE community strongly cautioned us that education should not play a role in a support group and that this would doubtlessly fail. Change is never comfortable. Our concept of “empowerment through education” was foreign and a step out of many people’s comfort zones. We are delighted at its success. Countless members across the globe have received an accurate diagnosis and positive treatment plan reaching best outcomes. We could never have imagined the amount of lives saved or lives improved with the birth of our mission.

As we mark this week by celebrating our first completed year as a Non-profit, we look back on a year that enabled us to make greater strides in advocacy than we had envisioned a year ago. We extend our thanks and love to our AE Family. You are all Warriors Extraordinaire and it is our privilege to work with you and beside you as we raise awareness of Autoimmune Encephalitis and help to improve the lives of the people who suffer from these disorders.