A Conversation with the Wheelchair Kamikaze

Marc Stecker, also known as the Wheelchair Kamikaze, has been sharing his perspective and experiences through his blog as he’s navigated his life with MS since 2009. Ranging from heartfelt, to humorous, to candid, to persuasive, his posts are intended to share with, inform, and entertain his readers. With more than 3 million page views since its inception, the Wheelchair Kamikaze blog is interesting and compelling reading for anyone, whether you have MS or not.

According to Marc, “The blog has put some method to the madness of my getting sick. I’m of mixed minds when it comes to subjects like fate, but the fact that Wheelchair Kamikaze may have, if even in the smallest of ways, helped some of my fellow members in this club that none of us ever wanted to join feel a little less overwhelmed by it all, then I am forever humbled and graced.”

Marc grew up in New York City, where he currently resides. He studied film at Boston University and was the lead singer in a punk rock band in the 1980’s. After school he lived in South Florida for about 10 years, during which he broke into the world of corporate video production and television. Eventually he followed his heart and returned to New York City. He was soon working freelance as a video editor and was eventually hired at Sony Music Studios as head of their DVD production department. It was an exciting place to work, with celebrities everywhere, but Marc wasn’t
content. He always had literary aspirations, and the administrative duties at Sony Music Studios weren’t creative enough.

Marc was diagnosed with primary progressive MS in 2003 and was forced to retire in 2007. At that time he was an active member of several online MS forums. As he learned more about MS, he tried to pass on what he was learning to other forum members, many of whom encouraged him to start blogging. Before his diagnosis, Marc was also an avid amateur photographer. However, his disability soon made it impossible for him to lift a camera to his eye. Encouraging him to continue to follow his passion, Marc’s wife gave him a flexible tripod and a camera with video capabilities and a flip out view screen. This made it so Marc didn’t have to lift the camera to his eye in order to take the pictures and movies that he enjoyed so much. Reluctantly at first, he hooked the tripod and camera up to his wheelchair, began taping videos of New York City excursions in his wheelchair (often while driving at full speed, hence the name “Wheelchair Kamikaze”) and doing voiceover narration of them. He sent them to friends and family who, thinking they had viral potential, encouraged him to share them more broadly. According to Marc, “before I got the wheelchair I was so limited, I was housebound. I got the wheelchair very reluctantly and suddenly the whole world opened up to me and I spent countless hours exploring every nook and cranny of Central Park. I had unlimited time, and was taking pictures. Central Park became my muse. The wheelchair awakened in me a lot of passions that had lain dormant for decades. I rediscovered who I was. It allowed me to follow passions I’d dreamed of until my disease became more invasive.” Marc’s blog started about 6 months after he got his wheelchair as a repository for his videos and photos. He never expected more than a dozen friends and family to ever look at them. He then started writing and the rest is history.

Marc’s blogs are driven by the latest MS research and his own experiences with the disease. When he was less disabled, he was out interacting with people and taking pictures, which would also spur ideas. Wheelchair Kamikaze has a wide audience that includes MS patients, patients with other chronic illnesses, neurologists, as well as people that are healthy. Marc remembers being astounded by the first email from someone who read his posts. Around 2010, Marc blogged about a new, alternative theory of MS involving blood flow in MS patients. As interest in the theory grew, so did the number of page views on Wheelchair Kamikaze, going from a few dozen page hits per day to thousands. Marc received emails from people all over the world. The craze on the theory came and went, but the popularity of Marc’s writing remains. Although he posts less frequently these days, he enjoys interacting with his readers and tries to answer as many emails as he can, as personally as he
can. According to Marc, “The impact is far beyond anything I would have imagined. The hope is that it illuminates not only life with MS, but a little bit of the human condition.”

As depicted in one of Marc’s popular videos, Wheelchair Kamikaze: Dash Down Amsterdam, people with MS in wheelchairs face many physical challenges and obstacles while functioning in their daily lives. In our interview, he also shares his insight and perspective on some of the more psychological aspects of dealing with increasing disability, such as appreciating time as a gift that shouldn’t be taken for granted. In addition, Marc shares some positives from his journey with MS. MS has helped him learn to forgive others (and himself), he’s learned precisely where his passions and priorities lie, and to value the people that he loves. In facing the challenges of daily living with MS, Marc has learned he’s much tougher than he ever imagined he could be.

Recent research results have often fueled Marc’s posts. Recently, he is most passionate about research that is geared toward finding a cure for MS. Marc has never participated in a clinical trial, but has tried a number of alternative therapies. As described in his blog, Marc does a cycle of the Fast Mimicking Diet once every 6 - 8 weeks. He’s also tried intravenous glutathione (an anti-oxidant) and acupuncture (both western and traditional Chinese). He sees a Naturopathic doctor who is a part of the neurology practice he goes to for his care. On her advice, he is taking a number of supplements, which help symptomatically. Of interest, Marc plans to post a 90-minute interview with her on his website in the near future, containing many actionable items that people can take advantage of.

Marc has been involved with ACP for a long time, participating in both the Repository and iConquerMS™. With regards to iConquerMS, Marc states, “being able to take a look at data from thousands of patients and being able to analyze all of the data could lead to tremendous breakthroughs. It’s a tremendously valuable project and is definitely on the right track…iConquerMS needs to get to critical mass that is truly indicative of a cross section of the entire MS population. Then it could be a game changer. The team they’ve assembled is incredible and dedicated. I’m confident we’ll figure out a way to get there.”

Marc generously allowed us to tape the interview for this article. If you’re interested in listening to Marc share his experiences and perspective, please click here. Whether you have MS or not, stay tuned to Wheelchair Kamikaze. You will be entertained, touched, informed and left wanting to read more!