

# The New Direction of My Youtube Channel

Since the creation of my Youtube channel in January 2017, my primary focus has been on Biogen, and their development of Spinraza (Nusinersen) and the approval which occurred in December 2016.

While I created my YouTube channel to document my journey as I started treatments, I found myself not only documented my journey, I was also documenting the journey of others. My channel became a source of information for many of you who, like me, began our journey wanting and needing information on what we needed to do to receive this potentially life-changing treatment.

The creation of Spinraza sent chills of excitement through every one of us, because this was the first treatment that had ever been approved by the U.S. Food & Drug Administration, (FDA). We were witnessing history in the making because until Spinraza became available, there was little hope that we had seen, and for many of us, the time clock was ticking much louder, and the sense of urgency was fast approaching.

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Many of us began speaking with our neurologists trying to find out whether or not they were going to take part in this treatment. While the journey was simple for most, some of us experienced challenges when trying to find treatment centers that were approved to administer the intrathecal injections that we were going to need.

Once we found the treatment centers that were approved, the next journey of filling out all the paperwork and waiting on approval from our insurance companies began. Waiting on our insurance companies to approve treatment turned out to be an arduous undertaking, but after waiting what seemed to be an exorbitant amount of time, most of us were approved either from our insurance companies, or we were approved through Biogen and their free drug program.

smajourney51

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One of the many kudos that I can give Biogen was their primary hope that nobody would be turned down for this treatment based on their inability to pay for it. Many pharmaceuticals make promises that they don't keep, but Biogen stood true to their word, especially with me. Once I'd been turned down from my insurance company, Biogen knew that my only hope of receiving this treatment would have to come from their free drug program. Biogen stepped up to the plate, and without them, I would've never received my treatments.

Many of the infants and children that are on this treatment will probably never know what it's like to sit in a wheelchair. Children and infants that have not experienced the muscle atrophy and muscle loss that those of us who are adults have experienced, will probably be the biggest benefactors of this treatment. Spinraza will probably allow them to grow up with the ability to walk and function as able-bodied citizens.

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Those of us who are older, such as myself, may experience slight muscle gain, but we will probably see a leveling off of our disease so that we do not get any worse as we get older. If this treatment doesn't do anything for me other than leveling off my disease so I don't get any worse in the future, I will count my blessings and thank my Lord and Savior Jesus Christ that I was allowed to go on this journey.

I will always be indebted to Biogen for their promise of not only getting me on this treatment, but also keeping me on the treatment until other alternative funding becomes available. With this being said, I also have a responsibility to not only myself, but to those of you who subscribe to my YouTube channel and follow me on my other social media accounts, to keep us informed of not only what Biogen is doing, but to also keep us up to date on new treatments that are going to become available in the near future.

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I am in no way abandoning Biogen and their plans for future SMA treatments. Biogen was the first to bring a treatment to those of us with Spinal Muscular Atrophy, and my primary focus will always be on Biogen and their future plans for those of us that are on their treatment. While we were all excited about what Biogen has done for us regarding our disease, I also feel that it is important to look into other treatments that are going to be presented to us in the not so distant future.

## Areas of Interest

- Other pharmaceutical companies and their development of new SMA treatments.
- Specific timelines for these new treatments for SMA.
- Specific news articles which detail these treatments and links with phone numbers and contacts for my subscribers to use to help them in their research for their families.
- Monthly question and answer videos to better address detailed questions I receive from my Youtube subscribers and Twitter followers addressing new and upcoming treatments.

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What I Need From You:

- This will involve extensive research on my part, so if you find articles on the Internet that explain new treatments, please send a link of the article to my email account: [smajourney51@gmail.com](mailto:smajourney51@gmail.com)
- While I'm going to do my best to gather this information, patience on your part will be greatly appreciated. Do not hesitate to make suggestions or make recommendations that I look elsewhere for information because you will not offend me.
- Please don't expect me to have all the answers. I created my Youtube channel to help keep all of us informed as to our treatment options, and with your help, I truly think the future of SMA treatments will surprise all of us.

## Final Thoughts

We have so much to look forward to in the coming years. Biogen has given many of us a new lease on life. I believe we all have a bright future ahead of us, and given the amount of attention that SMA has received over the past year, and the number of pharmaceutical companies actively working on treatments for SMA, the glass is not half empty, it's half full.