

62 Betaseron Stories & Tips



I just
switched to
Betaseron &
dont know
what to
expect.

352,388  **myspace** READERS



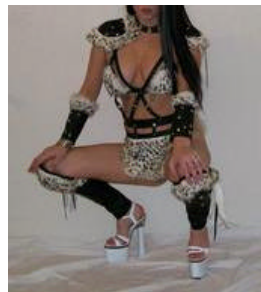
I am on Beta and it continues to help me. Just watch for side effects and call your NEURO at first sign of any! Put on your Game Face, get angry and prepare for Battle! Take your meds, stretch several times a day, Strength build regularly, (ask Neuro for a PT Consult), watch your diet, and Stay Connected to a support network. Knowledge is also powerful so learn all you can and know that there is always more to learn. Anytime you need to vent or refuel your determination we're all here for you!

Posted by Alpha



The very first treatment I was on was Betaseron. Betaseron is an interferon which is given every other day.

While I was on Betaseron I felt like I was on the edge of a nervous breakdown every waking minute of the day. I also contemplated my suicide everyday. It was awful. The funny thing was I couldn't distinguish if the feeling and thoughts I was having were my own or not because it was all so real for me. It took me six months to read the drug information paper that came with the drug. In that paper there was information about what happened when the drug went through the drug study. I had found out that a very small few of the people who were given the drug had taken their life and I think one person had attempted to but thankfully failed. After reading this I realized I was having a side effect to the medicine and I called my Doctor to let him know I would be getting off of the medicine. In about two weeks of being off of it I had returned to being myself. After this I started to read the drug information before any drug went into my body. Posted by Jesse

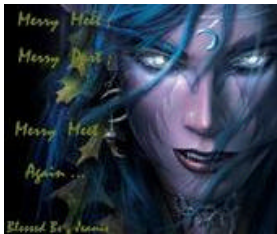


Now for the Betaseron-that's what I'm on-and for me the flu like mess was only the night I took the shot-and I took it at bedtime with a Tylenol or Advil---Ibuprofen is good too-I just can't use it...allergic...-beforehand and had one ready at bed side in case I woke up with any problems which only happened 2 or 3 times in a 4 month period...I only had them 4 mos anyway...after that I didn't even need the Tylenol anymore...Ice pack for any skin site reaction-and Benadryl (sp) cream on the shot site....I was told by my Beta nurse to take an antihistamine before too but I'm on Antivert which is the same as Dramamine (antihistamine) so I timed my dose of it to coincide with shot time...it wasn't fun but it wasn't "awful"....and with time it leveled out and became "old hat"...no big deal to me....Beta comes with access to MS Pathways-and your own personal Beta nurse who will help you out with things ya want to know-and 24/7 access to a Beta nurse that is happy to give support-answer things at 4 in the morning if you need 'em....

You'll be ok...As for whether it works-it's like all CRAB drugs-some work for some and not others-much the same as ANY med.... Shame you didn't know about the program that the Beta company has for those that can't afford Beta-or PPA so you could have already been on something....just remember when the shots get worrisome after a while of every other day-every time you take one your telling this monster MS "Take THAT you won't get me" More hugs and the best of luck-Beta has helped soooo many and you are doing the right thing to start that fight back at it... Posted by Anne



Here's a tip on Beta. You can titrate up and most people who do don't get the sides AT ALL! First time I did this I had no sides but still took tylenol and advil before a shot just in case. Now I'm up to full dose and at worst I get a bad headache so that's nothing! You can still have kids just have to discuss with your neuro when you want to and come off the Beta. I did meet one lady who is a doc who did it and stayed on the Beta I was shocked but she said from research she'd seen there really hadn't been any issues so she did it and her baby's perfectly fine. I wouldn't chance it though personally! In fact when I got prego I went off EVERYTHING!! Anywho long story short Beta is good and you can titrate check their website about it and ask your doc to tell the people at Beta when they come out to train you to titrate up :) Good luck! Sarah



I was only recently dx [well almost 9 months now] and my doc put me betaseron. At first I had pains in my joints like with the flu. Then the headaches started. Slowly over about 6 weeks they stopped. And now every so often I get them. And I can't take many of the over-the-counter pain killers due to my other meds. Anyway I feel better than I've felt in years. My Doc seems to think I've had MS. for a long time. Anyway I was also told you might have weight gain at first, I did but now I'm losing the weight . And something for fluid build up too. Now the only real problem I have now is I get real sleepy about an hour after I take my shot. But if you can stay awake it wears off. I drink coffee before I take my shot. It helps me. I truly hope Betaseron works for you. I give you many HUGS, lots of HOPE, and GRACIOUS PRAYERS. Be Blessed , Jeanie

Sorry, I forgot . They told me it took 6 months to go to work fully. And that's about how long it took to fully work. Take Care. Any Questions don't hesitate to ask. Also the company that makes Betaseron gave me a nurse. That I can call any time day or night if I have any questions also. So ask about that. I have a 1-800 number if you'd like. Just e-mail/message me for it. Jeanie



I am currently on Beta after being on AVONEX for a year, I take a Motrin about an hour before shot time which is at night and I am usually fine occasionally I'll wake up a little achy or with the sweats in the middle of the night but that is very

seldom. The BETA nurse is very helpful and they sent out a nurse to walk me through my first shot and I felt so much better. I know everything will work out. Take care!!! Posted by Melissa

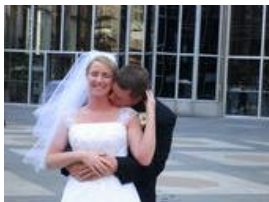


I'm on betaseron, and I'm very sensitive to the flu like symptoms. Before starting it, I was already on Welbutrin XL, which I stayed on while pregnant (it was safe to do so). HOWEVER, Betaseron is making my depression worse. So I'm on Lexapro at night, Welbutrin and Provigil during the day. I also suffer from migraines (since grade school), and right now I have a whopper that started last night and I woke up with it still there. My pain

meds aren't working :P

Everyone is different. I think it's ironic that I am a needlephobic and my medication involves needles :P

So, have your ice pack handy, and be sure to call your beta nurse for anything. They are really good with helping out :) Posted by Blackbird



Personally, I am on Betaseron and I love it. (I was on Avonex and hated the needle and it didn't seem to be working for me). Betaseron is so easy with the auto-injector. The ONLY problems I've has with it are very minor injection site reactions. Also, I usually take something like tylenol or advil 1 hour before b/c I tend to get a bit achy, but nothing major.

Since I've been on Betaseron I've been doing really well too, so again, I LOVE it. But which ever one you choose, good for you for getting on something!!! Good luck!! Posted by Beth

It is soooo convenient that Betaseron does not need refrigerated. I'm running all over the place like a crazy person and I always stash one or 2 shots in my bag, just in case. Luv it



I am on the Betaseron...Only minor side effects in the beginning with low grade fever. Didn't last a week. Doing great with it. Even get called by a Beta nurse every month to check on me! It is one I've my main weapons in my arsenal to fight the MS. No matter which you choose ask the Neuro for a PT referral too. The exercise just enhances what the meds do! Good luck! Posted by Alpha

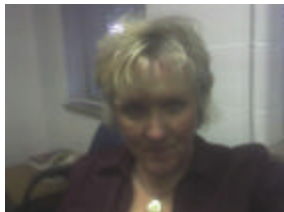


I used Beta-and I had no major problems-I took it about 6 in the evening-went to bed around 9 or 10-and had no reactions till about midnight-I took Tylenol extra strength...or Aleve-before the shot-and kept one by the bed and a glass of water in case I needed it...and I did need it for about 4 mos-then no more flu---

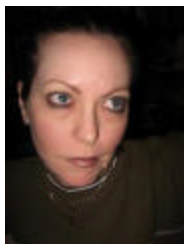
had three or 4 major shot site reactions but the Beta nurse with Pathways told me how to stop that-in squeezing air out make sure NO medicine gets on the outside of the needle...a tiny bit of air in the fatty tissue hurts nothing but med on the needle can cause necrosis (skin rotting basically) and I had one like that on my stomach for months.....she was right too as soon as I stopped letting med get on the outside of the needle I stopped getting site reactions- iced the spot before injection and rubbed it down a min or two after-the Beta nurse called it rubbing the medicine down- anyway...and used Benadryl creme on the site if it itched afterwards...Beta nurse also told me take a Benadryl before it but I'm on Antivert which is an antihistamine so that worked great...Posted by Anne



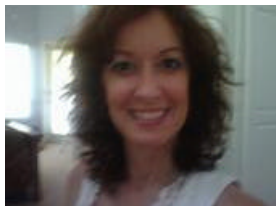
I have been using the Betaseron for a long time! The only side effects I had was for the first couple weeks I had flu like symptoms. My Beta Nurse told me to take tylenol an hour before the injection. The Beta Nurse will teach to give your self the shot with the autoinjector (Much easier) and the betaseron doesn't need to refrigerated!!!! Good Luck if you need any more information after you get started go ahead and add me or just post a comment here and you'll get a whole army of Angels helping you! Posted by Alpha



I was diagnosed in June 2004 and started Betaseron immediately and have been injecting myself ever since. So far so good, outside of the flulike side effects that I manage with ibuprofen. I inject every other night before I go to bed and take the ibuprofen just prior to my injection or as soon as possible thereafter. The nurses at Betaseron are supportive too and will call you a lot at first until you get the hang of it and feel comfortable. They are also available by phone 24/7 in case you have questions or concerns. I take an anti-depressant, Effexor XR. I started on that about a year after my original diagnosis. Whether the Betaseron caused it, I can't say, but I lean more towards the MS being the culprit and dealing with new feelings. ~Shirley



I've been on Betaseron for 11 years. the best things I've found for combating side effects are: drink lots of water & take ibuprofen before the shot. My side effects were heinous for the 1st month or 2, but they became less severe over time. GOOD LUCK! I'm sure you'll do just fine! Posted by adrienne*



I've always taken Advil liquigels for my flu like symptoms. I like that, unlike tylenol, ibupofen goes thru the kidneys, not

the liver. All the MS meds go thru the liver, so I only take tylenol before infusions. (IVIG) I have turned many friends on to the Liquigels too. They work fast and you can take 3 and feel better in 20 to 30 minutes. I'm not a doctor , but it works for me!

I don't know how long you've been on Beta, but I know the flu like symptoms usually fade around the 6 month to 8 month mark. Good Luck & you look marvelous! Live, Love, Laugh, Steph



I'm on Betaseron and have been for 4 years. I can only share my experience with you since we're all different and react differently as a result. Starting with the 1/4 dose and gradually increasing to the full dose by month's end is a kind and gentle introduction. Still it took me a few more months to adjust to the full dose and managing the flulike symptoms.

After 4 years I still get an occasional fluishness the day after my shot but it generally only lasts until around midday. Ibuprofen (Advil..whatever) is my drug of choice. I take 3 prior to my shot and 3 the next morning and sometimes throughout the next day or whenever I start to feel that flu-type feeling. Regardless, my point is that it's manageable for most of us that are on Betaseron. The Betaseron nurses at the 24/7 helpline are very helpful and will call and check on you periodically. Never hesitate to use them as a resource for assistance. That's what they're there for. Also, please contact your Neuro if at anytime you feel that the med is making you sicker instead of better. ~Shirley



I too have been on Betaseron for almost a year now and I get horrible side effects still. They tell you they lessen over time but that has not been my case. I do not get back pain, but I do have the full body aching like the flu. I get headaches and overall just feel shitty the day after I take my shots. I have learned that for me to get through the day I need to take Vicodin to combat the symptoms. I really don't want to rely on Vicodin but it's the only

thing I've found that works for me. Kathryn



I'VE BEEN ON BETASERON FOR ABOUT 4 YEARS AND HAVE NOT HAD ANY PROBLEMS!!..(WELL IN THE BEGINNING)....YOUR BODY HAS TO GET USED TO THE MEDS WETHER IT BE REBIF OR BETASERON . I HAD FLU LIKE SYMPTOMS THE FIRST TWO SHOTS THEN THE BETA NURSE INSTRUCTED ME TO TAKE MOTRIN 30 MINS BEFORE THE INJECTION! I STARTED DOIN THAT AND HAVE NOT HAD ANY SYMPTOMS TO DATE. I TOO HAD TO TAKE TWO DIFFERENT KITS HOME TO MAKE A DECISION I MADE MY DECISION BY TALKING TO DIFFERENT PEOPLE ON THOSE MEDS

AND CHECKING THE CLINICAL TRIALS FROM EACH ONE!! Posted by Lynn



Betaseron(R) to Offer the Thinnest Needle in Multiple Sclerosis

Bayer HealthCare Pharmaceuticals Inc. today announced that Betaseron(R)* (interferon beta-1b), its treatment for

relapsing forms of multiple sclerosis (MS), will soon be available with a new 30-gauge needle, which will be the thinnest needle of any injectable disease-modifying therapy for people with MS. The new needle is as thin as the needle commonly used for insulin and pediatric injections.

"The new Betaseron 30-gauge needle is a welcome advancement for people with MS, and particularly for those with anxiety about their injections." Issues around injections, such as injection anxiety, injection fatigue and injection site pain, are among the top reasons patients cite for not starting or continuing an injectable medication.(1) Betaseron therapy requires half as many injections as Copaxone(R)* (glatiramer acetate) with a needle that is 25 percent thinner.(2),(3) Additionally, in a study, significantly more Betaseron than Rebif(R)* patients were pain-free at all time points measured (immediately after injection, and 30 and 60 minutes after injection) over the course of 15 injections.(4) Also in that same study, Betaseron patients using the new 30-gauge needle reported more than 50 percent of their injections were pain-free immediately after injection.+ ++ (4)

The new thinnest, 30-gauge needle will be introduced with an optional new autoinjector called BETAJECT(R) Lite.*Section In a survey of patients who used the new 30-gauge needle along with the new autoinjector, 98 percent were "satisfied" or "very satisfied" with the new thinner needle and autoinjector after their first injection,(5) and nearly all of the patients who tried the BETAJECT LiteSection said the new autoinjector was easy to use.(5)

There have been no changes to the formulation or the mixing process of Betaseron -- it is still the same effective medication that patients and doctors have relied on for more than 15 years. People who are currently taking Betaseron can log onto www.betaseron.com/thinner for more information about the new needle and to request the optional BETAJECT Lite autoinjector.