

**Adults who have SMA Type 3, have lost walking ability and been treated with nusinersen in Serbia**

**June 2020**

**Adult A. 33 years old**

I was diagnosed with SMA Type 3 when I was 7 years old when the first symptoms were shown. Until the age of 32 the disease progression was constant, so I was losing strength, despite physical therapy. When I was about to begin treatment with spinraza, I felt bigger progression in my arms. Fingers on my hand started to convulse, also there were more morning coffee spilled accidents. I have noticed that it was harder for me to bath independently and living my daily routine. Spinraza world approval was in 2016. Since then and until my first dose, which was period of 3 years, progression took from me the ability to walk and stand independently. I was scared that progression will weaken my arms and that I will be more dependent on my family during my daily activities.

In Serbia we were lucky that the Ministry of Health understood our problems and need for this life saving treatment. My first dose was on September 19th 2019. Only a few days after the dose, convulsion in my fingers disappeared. After loading doses I started physical therapy and I felt the improvement. There are no more morning coffee spilled incidents, I don't feel fatigue while I'm bathing. Now my days are fulfilled with more activities, because I feel stronger. I hope I will be able to stand independently and make a few steps again. I am aware that this is only the beginning and that I have to put a lot of effort to be able to do much more. Every dose will bring me closer to that goal.

**Adult B. 30 years old**

I was diagnosed with SMA at the age of 3, the same year when my younger sister was born. She is also diagnosed with SMA Type 3. Before we received Spinraza the only thing we could do to slow down the progression was physical therapy as well as taking vitamins. She started using a wheelchair at the age of 10 and I was 17 when walking long distances became too hard. We feel that being able to receive Spinraza is a blessing. We both had *spinal* surgery and there was a fear that it would be impossible to get the injection. There were some complications during procedures but luckily our doctor succeeded in injecting the medicine. We feel improvements in our hands and arms; our necks are stronger, and we have more strength in general. She has more strength when coughing and can lift a full cup of tea easier. I have more stability when standing and I can make a few steps easier.

**Adult C age 36 years old**

Before starting Spinraza treatment I had lost my ability to walk. Since I've started receiving Spinraza, I feel a slight improvement after each dose, especially after the last, fifth dose. I don't feel only that the progression is stopped but also I noticed that my muscles are getting a little stronger. I can do some small movements I couldn't do before.

I feel better muscle activation while doing exercises, less *fatigue*, less back pain and more endurance. In general, the feeling is better in the whole body, the pressure and heaviness I felt before are relieving now.

**Adult who has SMA Type 3, has lost walking ability and been treated with nusinersen in Belgium**

**Adult D age 43 years**

**September 2020**

I was born in Brussels and I have Type III Spinal muscular atrophy. I had lost my walking ability before I started Spinraza treatment. I will receive my tenth Spinraza injection in November 2020. This medication has clearly stabilized the course of my illness. The movement scales used in the SMA (HFMSE) show a clearly positive development in my motor function since the first injection in September 2018.

I went from 35 points to 47 points since the start of treatment. Since that day, I have been able to observe better balance, better endurance, less fatigue, less tremor, lightness in my movements as well as functional recovery. Strength, deep stabilization.

I work as a political expert at SPW Economy. I am also involved in the Belgian Association against NeuroMuscular Diseases and in SMA Belgium. We join forces with Spierziekten Vlaanderen to make our voices heard as part of Spinal Amyotrophy. Spinraza has demonstrated its effectiveness in children and also in adults, all types combined. Spinraza provides the missing protein: Survival Motor Neurone. Various scientific articles support our remarks and prove the effectiveness of new drugs.

Most studies have been done on a young population, but a few articles are devoted to the effects of drugs on adults. Given the diversity of motor impairment in SMA, the manifestations are different depending on Types I, II and III and on age. The drugs provide a minimum of stabilization and a maximum, a functional gain, powerful motor of life. Every day, we communicate with people living in Europe, Canada or the United States and we all see a marked improvement in our quality of life.

So many new scientific advances and new healing paths are underway for patients with Spinal Amyotrophy. This must continue! Sometimes it is better to have a nice report than long sentences, so I invite you to [watch the video made in Saint Luc university clinics about Spinraza](#).

**29<sup>th</sup> October 2020**

I personally still walk but with 2 crutches for a very short distance maximum 50 metres (I'm considered as no ambulant as I need 2 crutches to walk). One year after my first spinraza injection, I regain the ability to walk for 5 or 6 steps without crutches. Without Spinraza I'm sure that I would have lost the ability to walk, even with crutches.

**Adult who has SMA Type 3, has lost walking ability and been treated with nusinersen in France**

**Adult E age 24 years**

**2nd November 2020,**

I'm 24 years old and diagnosed with SMA type 3 for 22 years. In my 10th year I've lost the ability to walk.

For some years I've been swimming once a week for at least 30 minutes and I've been going to the gym at least once. I knew that if I was not doing this amount of sport, I could lose my muscles and my freedom.

In late August 2019 I received my first injection of SPINRAZA. In February 2021 I will receive the 8th one.

During the first two months I felt more powerful with less tiredness after an effort. I'm also able now to exercise a new movement: when I'm sitting on my feet, knees against the floor I can stand up on knees without the help of my arms. I can't do this movement every time and with a lot of repetitions, but it was a success for me.

So, during those first two months I received 4 injections, now I have one injection every 4 months. The first time I had to wait 4 months for my injection, during the last two weeks I felt that I was losing strength and was very tired, my body was missing something.

Afterwards it was the quarantine for almost 2 months, I didn't have any physiotherapy or couldn't swim and go to the gym. I was very stressed with the fact of losing strength, but I DIDN'T ! I think the injections allow me to not lose what I earned before and allow me to skip sports sometimes without fearing the fact of losing muscles.

My life is new since I have received this treatment.

For the bad effects, those are only during the time of the injection. The time at the hospital (2days) is long for just one hour of injection. Then the injection is sometimes painful, I had felt some back pain during the few hours after, but it never lasted a long time.

I also had once a headache.

Otherwise, NO BAD EFFECTS !