



# Kämpft mit Ben!

Hi,

my name is Ben.

I urgently need your help because I am suffering from SMA type 2 (Spinal Muscular Atrophy type 2). This highly debilitating illness will never let me learn to walk or play with my sister and friends on the playground. The doctors have informed me that I will be wheelchair bound until I am about 20 years old, by which time my muscles and respiration will have broken down and my time will have come to an end.

However, there is hope! One single dose of the drug Zolgensma, which has achieved significant results during the medical treatment for patients that suffer from SMA type 2 in the U.S., will hopefully stop the degeneration of my muscles and significantly extend my lifetime.

It is a serious game changer for all young SMA patients like myself. My hopes are that I will be able to move my limbs more and grow to be as old as Nana and Grandpa. This single dose drug should mean I can avoid the long life therapy of another drug which I would otherwise have to be given every 4 months through a lumbar puncture combined with a 3 day stay at the hospital. With all the potential benefits of Zolgensma I still have several hurdles to surmount before I can even begin this special treatment.

- Zolgensma is, up to this point, missing medical approval by the EMA for use in Europe.
- Zolgensma's is very expensive with a total cost of nearly €2 Million (2.1 Million \$US).
- Zolgensma is currently not covered by my health insurance.
- Because of the EMA restrictions it is difficult to find a qualified and willing doctor who is able to administer the Zolgensma.

This rare and special drug Zolgensma has to be administered to me before I turn 2 years old. As you read this I am 15 months old and counting. I cannot wait for the missing regulatory approval and neither can I expect an immediate change to the insurance policy, the time is now.

So please join with me in my fight for the very best that medical science has to offer. I need every single one of you to give me whatever help you can! If I am successful in my quest I hope it will set new precedents for access to this special treatment and that it will become standard practise for those in similar positions as myself.

You can help by donating towards my cause and if it works out you will see me enjoy a quality of life where I can at least play with my sister and hopefully live to a grand old age like my lovely grandparents. I and my amazing family will be forever grateful for any assistance you can give.

Thank you all so very much,

Yours, Ben Herrmann

## Donation Account

Holder: Deutsche Muskelstiftung  
IBAN: DE97 6602 0500 0008 7390 04  
Reference: Ben Herrmann

Mag und Chris Herrmann [info@kaempft-mit-ben.de](mailto:info@kaempft-mit-ben.de)



[www.kaempft-mit-ben.de](http://www.kaempft-mit-ben.de)



@kaempft\_mit\_ben



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\* All donations will be used for treatment with Zolgensma and therapeutic measures for Ben Herrmann and are administered by 'Deutsche Muskelstiftung' for 2 years. In case that medicals costs are accepted by the health insurance the complete donations will go to 'Deutsche Muskelstiftung' at the end of 2 years.