

# APPEAL FOR DONATION for 8-years old **MATIC**

## from Slovenia

### WE MUST RAISE €2,2 MILLION FOR HIS TREATMENT

**Matic has Duchenne muscular dystrophy**, an extremely devastating, cruel, and merciless rare genetic disease, and his only hope lies in a **new gene therapy Elevidys**, which is available in the USA.

Matic urgently needs this treatment!

Matic's parents need to raise €2,2 million for this treatment with gene therapy in the USA. They have launched a fundraising campaign led by Viljem Julijan Association. (Društvo Viljem Julijan), with additional support from the Initiative for Matic from his hometown Škofja Loka in Slovenia.



[Webpage for Matic](#)



[Facebook page of Viljem Julijan Association](#)



[Instagram page of Viljem Julijan Association](#)



[Facebook page A gene therapy for Matic](#)



[Instagram page A gene therapy for Matic](#)

# BECOME A DONOR

## Please help Matic with a donation

Every single donation counts, and with every contribution, we are one step closer to our goal.



### SPECIAL DONATIONS:



**DIAMANT DONOR**  
20.000 € and more



**GOLD DONOR**  
10.000 €

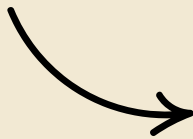


**SILVER DONOR**  
5.000 €

**You can make a donation for Matic - for the gene therapy Elevidys:**

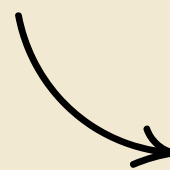
**A** Through international **GoGetFunding** platform

QR code for GoGetFunding website:



<https://gogetfunding.com/hope-for-matic-lets-raise-e22-million-for-his-medication/>

**B** OR donate quickly and securely via the **Stripe** payment system:



**C** OR via transfer to bank account of **Viljem Julijan Association:**

- **SI56 0400 0028 1688 717**
- **Reference: SI00 444777**
- **Purpose: »For Matic«**
- **SWIFT bank code: KBMASI2X (OTP banka d.d.)**

Address: Viljem Julijan Association for Children with Rare Diseases  
Cesta Leona Dobrotinška 2, 3230 Šentjur, Slovenia, VAT number: 98136399, Registration number: 4107870000

Viljem Julijan Association is an officially registered humanitarian organization.

*Thank you for your donation!*

# HOPE FOR MATIC

Let's give Matic a hope for life.



**8-year-old Matic from town Škofja Loka in Slovenia suffers from an extremely devastating, cruel, and merciless rare genetic disease - Duchenne muscular dystrophy - for which there was, until recently, no treatment. However, a revolutionary new gene therapy Elevidys has recently been developed and approved in the United States, giving patients hope for a new life.**

Since the gene therapy has not yet been approved in Europe, Matic can only receive it if his family takes him to the USA and pays for the treatment themselves. The gene therapy, along with treatment costs, amounts to €3.2 million. Matic's parents are using all their savings and taking out loans to cover the costs, but this will not be enough. **Thus, Matic's only hope of receiving the treatment is to raise the remaining €2.2 million through donations.** A major fundraising campaign is led by **the Viljem Julijan Association**, with additional support from the **Initiative for Matic**.

Charming and cheerful Matic, who turned 8 in January 2025, was diagnosed at 11 months of age with a severe, cruel, incurable, and rapidly progressive genetic disease called Duchenne Muscular Dystrophy. **The disease causes unstoppable degeneration and breakdown of muscles throughout the body, progressing rapidly after the age of 7 to 8. As a result, patients typically lose the ability to walk between the ages of 10 and 12 and are permanently confined to a wheelchair.** Afterward, they gradually lose other motor functions and become practically paralyzed from the neck down, often with spinal deformities and joint problems. **Because the disease also affects the respiratory and heart muscles as well, patients face increasing cardiac and respiratory problems, and life expectancy rarely extends beyond their 20s. The average life span of individuals with this condition is just 28 years.**



# RACE AGAINST TIME

Matic urgently needs the Elevidys treatment.



MATIC WITH HIS PARENTS, ŽIVA KRELJ AND TADEJ ŽONTAR

“*When we learned about Matic's diagnosis, our world collapsed. We were devastated and completely desperate because the doctors told us that there was no cure or treatment for his disease, that he would face a very difficult life, that he would soon end up in a wheelchair, and that his life would be very short,» say his parents, Živa Krelj and Tadej Žontar from town Škofja Loka in Slovenia.* »For parents, there is nothing worse than to watch helplessly as your child deteriorates in front of your eyes and not be able to help. But we decided we wouldn't give up. **With unwavering faith and optimism, we decided that we would do everything in our power to ensure that Matic would one day have the chance to receive treatment.** Even back then, there was information that medicines were in development and might be approved within a few years. The hope that treatment will be available has kept us going. The promise of a future where these breakthrough solutions could become a reality became our purpose. We poured all our energy into saving money, because we wanted to ensure we had enough to give Matic the chance of a treatment. We did everything in our power to make that happen. ”

# A REVOLUTIONARY TREATMENT

With gene therapy Elevidys.

Last year, the USA finally approved the first gene therapy for Duchenne muscular dystrophy, a revolutionary treatment called Elevidys. This long-awaited breakthrough offers new hope for patients. Like other gene therapies, Elevidys is a one-time treatment that introduces a shortened, healthy version of the dystrophin gene into the body, compensating for the defective or missing gene in patients. Initially, however, Elevidys was only approved for children up to the age of 6, which meant that Matic was ineligible for the treatment as he had already passed that age limit. Last summer, the USA expanded the approval of Elevidys to include patients over the age of 6, bringing extraordinary new hope for Matic but also introducing a significant new challenge.



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*When we saw videos of children in the USA who had received this treatment, we saw their progress, and read about the excitement of their parents, we knew that Matic had to get this treatment too. It is his only hope for a better future and a chance for life. However, when we learned how much Elevidys costs, we were in shock. We knew the treatment would be expensive, but we never imagined the price would be so unbelievably high - €3.2 million. At the time, it was also the most expensive medicine in the world. Despite years of doing everything we could to save money, we were faced with an insurmountable obstacle. It was an incredibly difficult time, but we knew we had to do everything we could for Matic because, without this treatment, he has no future. **The only option for Matic now is to raise the missing €2.2 million as soon as possible, because Matic must receive the medicine urgently** - otherwise it could be too late,« his parents said. »Matic has already turned 8, and this is the age when the disease begins to progress rapidly, soon leading to reliance on a wheelchair.*

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“ At the Viljem Julijan Association, we wish with all our hearts that Matic could receive the treatment with the Elevidys gene therapy, as we deeply understand how severe and devastating Duchenne muscular dystrophy is. That is why we are fully committed to supporting his family and the fundraising campaign for Matic. We believe that we can raise €2.2 million and make it possible for Matic to receive treatment in the USA. ”

**dr. Nejc Jelen, president of Viljem Julijan Association**



**MATIC WITH HIS PARENTS, BROTHER GAŠPER AND SISTER AJDA**

“ With hearts full of hope, we turn to you with an appeal for help. Any donation for our Matic will be greatly appreciated and will help fund the treatment that can make a huge difference to his life. This support will enable us to provide Matic with a bright future, full of hope and opportunity that he deserves. **We sincerely thank you for every contribution and for your support in this incredibly difficult situation.** We will be deeply grateful for every step you take with us. ”

**Živa in Tadej Žontar, Matic's parents**

**LET'S MAKE A DONATION TO Matic,  
SO HE CAN RECEIVE GENE THERAPY  
IN THE USA AS SOON AS POSSIBLE**





## Articles in Slovenian media:

- <https://www.24ur.com/novice/slovenija/edino-upanje-za-matica-genska-terapija-v-zda.html>
- <https://www.rtv slo.si/zdravje/zbirajo-sredstva-za-zdravilo-za-matica-ki-ima-neusmiljeno-bolezen-stars-iz-kanj-varcujejo-od-rojstva/730583>
- <https://www.rtv slo.si/dostopno/zbirajo-sredstva-za-zdravilo-za-matica/730705>
- <https://siol.net/novice/slovenija/v-drustvo-viljem-julijan-zagnali-zbiralno-akcijo-za-zdravilo-za-sedemletnega-matica-650729>
- <https://n1info.si/novice/slovenija/7-letni-matic-potrebuje-pomoc-ko-sva-izvedela-diagnozo-se-nama-je-sesul-svet/>
- <https://www.dnevnik.si/novice/slovenija/edina-bozicna-zelja-matica-in-njegove-druzine-2708627/>
- [https://www.24ur.com/video/iz-24ur-pomoc-maticu\\_63354740.html](https://www.24ur.com/video/iz-24ur-pomoc-maticu_63354740.html)
- <https://siol.net/novice/slovenija/za-zdravljenje-sedemletnega-matica-v-enem-tednu-zbrali-325-000-evrov-651291>
- <https://www.slovenskenovice.si/novice/slovenija/matic-7-iz-skofje-loke-ima-kruto-bolezen-a-zdravilo-stane-32-milijona-evrov-foto/>
- <https://www.24ur.com/novice/slovenija/matic-praznuje-8-rojstni-dan.html>
- <https://svet24.si/clanek/novice/slovenija/676fe7de999a1/za-zdravljenje-sedemletnega-matica-doslej-zbrali-610000-evrov>
- <https://siol.net/novice/slovenija/poziv-srcnim-slovcem-matic-za-zdravilo-potrebuje-se-dober-milijon-in-pol-evrov-651652>
- <https://n1info.si/novice/slovenija/osemletni-matic-za-zdravljenje-potrebuje-se-1-210-000-evrov-donacij/>
- <https://www.24ur.com/novice/slovenija/za-matica-zbrali-ze-610000-evrov-za-zdravljenje-v-zda-potrebuje-se-159-milijona-evrov.html>
- <https://www.metropolitan.si/novice/slovenija/zbiranje-denar-pomoc-otrok-matic-bolezen-zdravljenje/>
- <https://www.24ur.com/novice/slovenija/upava-na-bozicni-cudez-malemu-maticu-lahko-pomaga-le-zdravljenje-v-zda.html>
- <https://www.24ur.com/novice/slovenija/maticu-bi-za-rojstni-dan-radi-podarili-zdravljenje-v-zda-lahko-pomagate.html>
- <https://www.rtv slo.si/dostopno/clanki/za-matica-zbrana-polovica-potrebni-sredstev-za-zdravljenje-v-zda-cas-ni-njegov-zaveznik/733920>

# *We sincerely thank you for your donation and support for Matic!*

*dr. Nejc Jelen, the president of the Viljem Julijan Association*

*Miha Ješe, the president of the Initiative For Matic*

*Tine Radinja, honorary president of the Initiative For Matic*

## CONTACT

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**The Viljem Julijan Association is an officially registered humanitarian organization and an organization of public interest. It is also a full member of EURORDIS, the European Organisation for Rare Diseases.**

The Viljem Julijan Association has received support from:

- Yann Le Cama, President of the European Organisation for Rare Diseases - EURORDIS
- Minister of Health Samo Fakin
- Ombudsman Peter Svetina
- dr. Božidar Voljča, Chairman of the Slovenian Commission for Medical Ethics



