

# A young lawyer fighting to retrieve her face

## Who is Ivanka Danišová?

- She was born in 1987 in Bratislava.
- Ivanka suffers from Goldenhar syndrome in its most severe form. With combination of severe diagnosis and complications like these, there are 30 patients around the world.
- The first medical diagnosis said: she will not survive the first year of her life.
- Ivanka, however, has never given up: she survived bullying, completed legal studies, on top of that, she lost both of her parents.
- She lives and works in the Czech Republic where she pays the medical insurance.
- There is no experience with treatment of Goldenhar syndrome of such a severity in Europe, therefore, she has sought help in the USA and Japan.



## What is Goldenhar syndrome?

- It is a rare congenital development anomaly: a patient has incomplete facio-cranial bones, incomplete jaws, including the jaw joint, incomplete ear resulting in hearing apparatus disorder. In Ivanka's case, the most severe anomaly includes vision disorder, including the incomplete development of orbital bone.
- Ivanka has been fighting with leukaemia three times and faces a difficult heart fight - she has had 5 cardiac surgeries.

## What condition is Ivanka in?

- Doctors implanted her vital bone implants and Ivanka can now eat, speak and hear after 5 cranial surgeries.
- Just one more surgery in Japan was necessary to perform: this year in the winter, Ivanka raised 2 million Czech crowns through the fund.
- However, her happiness lasted not too long - just 24 hours – CT revealed a complication which is found in 1% of patients. A new bone is growing under the implants, causing extreme pain.
- **Therefore, it is necessary to perform an acute surgery in the USA.**

## Campaign #saveivanka

- A link for a public fund-raising campaign:

**[www.saveivanka.org](http://www.saveivanka.org)**

- Target group: people in the Czech Republic and USA
- Fund-raising campaign deadline: May 03, 2019

The price of surgery in the USA

**168 309 USD**



## Why the Insurance Agency may not help?

- The Insurance Agency refuses to cover the surgery.
- Just one month is left to pay for the surgery. In this situation, we did not even address the Insurance Agency because this deadline would not be met due to bureaucracy processes involved in applying for aid.

## How can you help?

- What we primarily need is supporting impact and strong personalities on social networks.
- You can do as little as, e.g.: taking a picture with a one half of a face covered (Ivanka's symbol), you can share information about the fund-raising or make a short video asking for help.

## What shall we offer?

- In addition to a good feeling, we offer a share in an international campaign which might change a lot – not only in Ivanka's case, yet in case of other patients.
- At the same time, you can spread information about the Goldenhar syndrome, which is also Ivanka's mission.

## Contacts

It is very important for us that you believe in what we do before supporting us. Do you want to know Ivanka's team in person? Do you have a question that remained unanswered? Contact us and we will be happy to answer.

**Katerina Etrychova / +420 736 531 105**