HAVING A CHILD WITH DOWN SYNDROME FROM MULTIPLE BIRTHS

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In Czechia approximately 50 children with Down syndrome (DS) are born every year (Table 1). The birth of twins or multiples in the DS population is therefore very rare (probability less than 0.1 %).

For the purposes of our presentation, we contacted families in Czechia with twins or triplets where one or two of the children were born with DS. All the children were born between years 2000 – 2017. None of the births were result of in vitro fertilization (IVF). All of commented births were premature, ranging from moderate (38th week of pregnancy) to heavy (30th week of pregnancy). Births of twins in 2000, 2001 and 2004 were without DS positive prenatal diagnosis and the labours were natural. Deliveries in last years were made exclusively by cesarean section. Most of the mentioned twins and triplets have another sibling. All these children are living in their natural (home) environment and were educated together with their siblings.



TABLE 1

NUMBER OF CHILDREN **BORN WITH DOWN** SYNDROME PER YEAR IN TOTAL (NUM.)

SOURCE: ÚZIS ČR, ANNUAL REPORT 2016, WWW.UZIS.CZ

"I got pregnant in June 2016 and it seemed to be twins. One week later, there was another ultrasound, where there appeared not 2 embryos, but 3. No one expected this, and after the initial shock we remained happy. During the screening at 13th week a high risk of trisomy 21 was detected. No one has dealt with this and no other tests were not recommended. At 30th week of pregnancy the triplets were born by acute cesarean section (because of bad condition of one of the fetuses): Stella, Jan and Filip - DS was confirmed shortly after the birth. After 4 weeks, Filip was operated due to necrotizing enterocolitis. Another surgery followed in 2 months. In spite of all complications everything went well. We are monitored in a risk counseling for preterm infants, neurology and endocrinology. Filip is very well and he has the great advantage of having siblings of the same age who motivate him."

At the 35th week of pregnancy, boys Vojta and Tomas were born after spontaneous delivery. There were feeding problems after the birth, the boys had to be probed, and Tomas was found to have a heart defect. And genetic tests confirmed chromosome trisomy of both boys. Due to a heart defect, Tomáš underwent operation. Boys are under supervision of neurologist, cardiologist, endocrinologist, ophthalmologist and ear specialist.

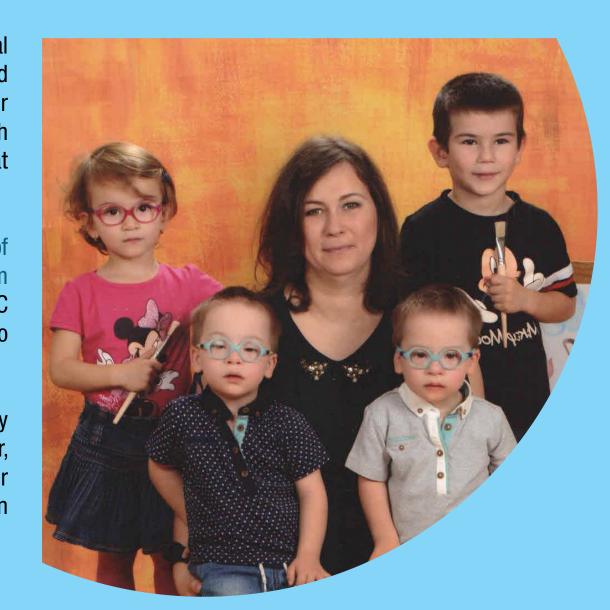
Despite all other things, me, my husband and our older sons, we all love our little boys, they are very smart, smiling and we are very happy with them.

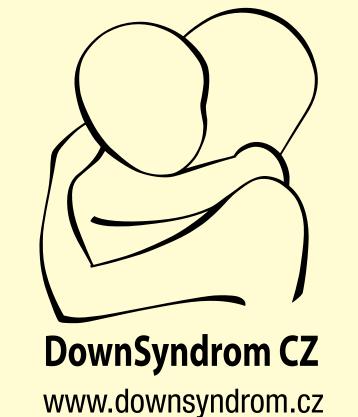


" In December 2013, my gynaecologist confirmed that I was pregnant: "Congratulations, it will be triplets," he said. He informed me they will be polyzygotic triplets (separate sacs, separate placentas). After the first shock, me and my husband we both were very happy, it was an unexpected gift for us. At that time we already had one son Peter, 14 months old. They referred me to a tertiary maternity hospital where specialists for both obstetric and premature baby care were available. Ultrasound in 12th week showed a positive screening of foetus C, 1:22, and I was offered an amniocentesis. After a discussion with my husband, we decided not to put two healthy babies in danger by such invasive examination. We accepted the fact one boy may have Down syndrome, but still hoped he will be alright. During pregnancy, I suffered only from gestational diabetes, and all following examinations were normal, not showing any abnormalities. Children were born at 32 + 3 weeks gestation by caesarean section. Two boys and a little girl, "a pair and a spare" - Zuzana 1860g, Martin 2130g and Tomáš 2134g. They all were just moderately preterm babies, they required four weeks of NICUcare, but nothing special: the first night both boys had CPAP and few weeks feeding by NGS and that was it. All three without any acute problem. Hearts without defects. We were told the very morning they were born that they suspect Martin and Tomáš to

We also found a very strong support in the Association of Parents and Friends of Children with DS (DownSyndrom CZ). Since the boys were 2 we started to go to SPC (Special pedagogic centre) every two weeks. We also visited speech therapist every month.

Currently the triplets are 4 years old and this year they started to go to the same regular preschool as Peter, their older brother. Boys are in the same class as their sister Zuzana. Martin and Tomáš both have their own assistant, who helps them with everything. '





Association of Parents and Friends of Children with DS

- Czech non-governmental association established in 1996 I Prague.
- A member of EDSA (European Down Syndrome Association, www.edsa.eu).
- Provides support and help for families with a person with Down syndrome.
- Successful programs include: support of skills development of the youngest children (music therapy, massages, early learning and reading), support for school inclusion, programs for teens and adults, summer and winter camps for families, lectures and seminars for parents.
- The Association publishes its own magazine PLUS 21.

PLUS 21

- ISSN 1213-1466, since 1999, 3 issues (36 pages) per year.
- Information platform and space for sharing not only parental experiences.
- The annual subscription (equivalent of 10 EUR) is intended for all interested parties. It is distributed freely to maternity hospitals, genetic workplaces, collaborating physicians, schools, non-profit associations,

teachers and more.

