

FUNDRAISING FOR ANNIE



APRIL 2015

THE PURPOSE OF THIS FUNDRAISING IS COLLECTING FUNDS TO SUPPORT THE MEDICAL PROGRAM OF A LITTLE GIRL ANNIE KRÁLOVÁ IN THE UNITED STATES OF AMERICA, AS WELL AS RELATED COSTS FOR ANNIE AND HER PARENTS.

Please help little Annie, who was born with a rare congenital defect known as radial aplasia. This physical disability caused by a missing radial bone in her arm, seriously affects the development of the whole arm, wrist bending and fundamental limitation of elbow, wrist and fingers movement. The unique surgery in the USA would significantly improve the function of Annie's left arm and thereby vastly improve the quality of her life.

ANNIE'S PARENTS ABOUT THEIR DAUGHTER

„Our Annie was born in January in 2014 and we looked forward to her very much. She is an adorable little girl. We admire her adventurous spirit and her big joy of life. Annie is a very smart and bright girl. She amazes us every single day how she is able to cope with everything. Unfortunately, her birth defect keeps her from doing many activities. They are, for example, the first attempts with getting dressed, putting on shoes, holding a cup or a toy, and riding a small bike. We try to involve Annie to various activities. We swim, exercise, play and do art. She likes drawing and she loves running on the playground or in a forest. It is charming to watch her being calm and concentrated at one time and being full of energy at another. Not only for these great qualities we would like to help her to her future life as much as possible. People often wear “pink glasses” and don't see the evident facts. Her handicap is fundamental and strongly limiting in many areas, but thanks to the surgery which allows her to use her forearm, wrist and fingers, she could be involved in an ordinary life and not to be socially excluded.“



JUNE 2015

**TRANSPARENT ACCOUNT FOR ANNIE IS
2500907126/2010**

Fio banka, a.s., IBAN: CZ122010000002500907126, BIC/SWIFT: FIOBCZPPXXX

Annie, Association to support children with handicap – Radial Club Hand

WWW.ANICKAKRALOVA.CZ

SOMETHING ABOUT THE SURGERY

Having contacted the parents of children with the same condition from all around the world, Annie's parents learned about the so-called ulnarization. The aim of the surgery and subsequent rehabilitation is to straighten the wrist and thus increase the functionality of the hand and fingers. **Current results of surgeries and in particular the experience of parents whose children have undergone the surgery show that ulnarization clearly improves the quality of life of people with radial aplasia.** Ulnarization is a complex procedure involving surgery, orthopedics etc., so it is not a plastic cosmetic surgery.

Currently, this surgery is only performed by a few doctors in the world, due to the complexity of the procedure and in particular due to the very small number of patients. Annie's parents got in touch with Dr. Shawn Standard of Sinai Hospital in Baltimore in the United States, who was recommended to them by many patients and their parents because of the great results he had achieved.

The surgery requires several days of hospitalization. Depending on individual condition, patient's arm must be stabilized for about three months by so-called external fixator. Afterwards, the arm must be in a cast from shoulder to the fingers for about 1-2 months. Then the physical therapy comes. **The total time that Annie needs to spend in the US with her parents is about 6 months.**

FINANCE

The whole procedure is not covered by health insurance, ulnarization itself costs \$ 52 000.

ON THE BASE OF THE REQUEST OF GIVING A PERMISSION TO COVER THE COSTS OF PLANNED SERVICES ABROAD, THE GENERAL INSURANCE COMPANY MADE AN OBLIGATORY STATEMENT OF GRANTING A REQUEST AND IT COVERS THE SPECIFIC HEALTH SERVICES.

Although the Insurance Company has decided to cover the surgery and it has supported Annie very much, this project is very demanding for the whole family. It deals with other costs related to the health program, particularly hospitalization, medication and rehabilitation in the USA, costs for air tickets, an accommodation for 6 months in the USA, regular medical check-ups connected again with traveling and accommodation. These costs are more than 1,000,000 Czech crowns. Annie's parents don't want to split the family for such a long time and they want to support Annie together. Their absence in the Czech Republic means interrupting the occupational contracts, thus the loss of salary but on the other hand they still must pay the financial obligations in the Czech Republic. That is why parents do their best to gain money for it and they kindly ask the public for help

ANNIE'S PARENTS' MESSAGE

„Much like any parents, we primarily strive to provide the best for our Annie. To provide a better future for her, significant improvement in the function of the hand and fingers, allowing her to better integrate in life; despite the many difficult steps, this is the only possible way to take.

However, after completing this project, we wish to continue helping all children with this condition. We have therefore established a non-profit organization to support children with the handicap – Radial Club Hand. We are also preparing a website containing all the information needed for children and their parents in a similar situation, providing counseling and edifying activities.

*Thank you very much. We do appreciate your help“
ANIČKA, HELENA and HONZA KRÁLOVI*



MORE ABOUT RADIAL APLASIA AND ULNARIZATION

RADIAL APLASIA

Radial aplasia is a very rare congenital defect, which occurs in about 1 to 100,000 births. It consists in undeveloped or only partially developed bone base of a radial bone. Aplasia has several grades, while in Annie's case, the condition is ranked as the highest grade of severe disability - complete absence of the radial bone. Ulna is shorter and slightly curved, the wrist is bent, perpendicular toward the thumb. As a result, fingers cannot be fully functional. The thumb is fully hypoplastic and thus totally unusable.

Annie has undergone many different tests for any associated defects, including genetic testing. So far any other accompanying defects or syndromes related to possible hereditary defect have been ruled out. **The result of genetic testing concludes that in Annie's case this is not a hereditary disease, but sporadic occurrence.**

ULNARIZATION

Ulnarization was invented by Dr. Dror Paley, Florida, US in 1998 and subsequently operated jointly with Dr. Shawn Standard, who is today a world-class in the field and operates in the so-called **Rubin Institute for Advanced Orthopedics at Sinai Hospital in Baltimore**, US. Results show that ulnarization improves hand functionality and thereby significantly improves the quality of life of individuals with radial aplasia. It is recommended to perform a surgery at the age of 1 or 2 but it is possible to perform it until a child is 6 years old.

Dr. Shawn Standard has performed ulnarization since 2002 and he recommends it because this procedure eliminates the risks of the previous surgeries as centralization / radialization.

The most important advantages of ulnarization:

- 1/ forearm and wrist remain free and the wrist may move, it is not necessary to wear any splint
- 2/ during 12 years this surgery has been implemented Dr. Standard has reported 0% rate of growth cartilage damage during surgery,
- 3/ the specific position of ulna to the wrist doesn't allow the wrist/hand may return to its original curved shape.

These results cannot be achieved using the previously implemented temporary intervention, the so called centralization or radialization, which leave the forearm and wrist firmly connected and thus disallow wrist movement; there is a risk of damage to the so-called growth cartilage, causing the bone growth slow or stop, and there is a very high probability that the wrist/hand will return to its original curved position, which involves subsequent repeated surgeries and prolonged physical therapy.

There is more information on the websites:

www.anickakralova.cz

CONTACTS

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Non-profit organization:

Annie, Association to support children with handicap – Radial Club Hand, IČO: 04540093



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