

# PALČEKOVIA LITTLE PEOPLE

OZ PALČEKOVIA  
M.RÁZUSA 46/15, 971 01 PRIEVIDZA  
SLOVAK REPUBLIC



*„PALČEKOVIA“ organization of people with a small  
statue but with a big heart.“*

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# PALČEKOVIA

## LITTLE PEOPLE



- *Coming from a slovak word „palec“ which means „thumb“ in english = small, always aside*
- *„Palček“ – person with Achondroplasia diagnosis*
- The organization has been established in a year 2011 based on the czech version of org. „Paleček“
- The idea came from a need to associate people with this disease



- year 2011 – 5 families – 19 people (6 „little people“)
- year 2018 – 35 families – 120 people (40 „little people“)
- 99% were healthy parents coming from different parts of Slovakia
- *2 hours (mixed couples) which have 5 children (2 „little people“)*

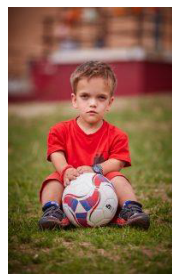
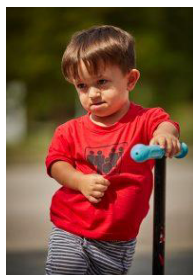
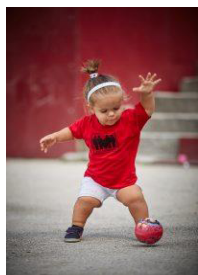


# MISSION :

- To make people realize and show them that they are not alone and despite this disability, they can enjoy their life
- To meet new people, network and find new friends
- To share our experiences and everyday's struggles
- To support each other
- To motivate and show others how to do things in a better way 😊



- To create exciting program full of fun while doing sport or playing games
- Fair play = *little person vs. little person*
- Presentations and discussions for parents led by professionals such as doctors, social workers or lawyers



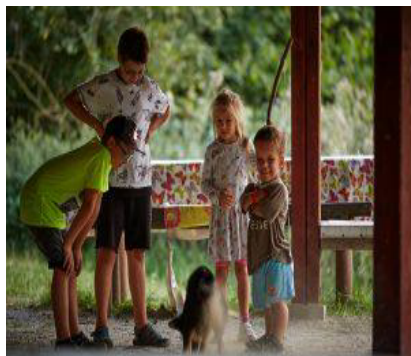
# PRAXIS IN SLOVAKIA

- Parents having children or expecting a child with Achonodroplasia diagnosed contact us
- Lack of professionals (specialized doctors, psychologists, teachers)
- We have to support parents and get rid of their worries



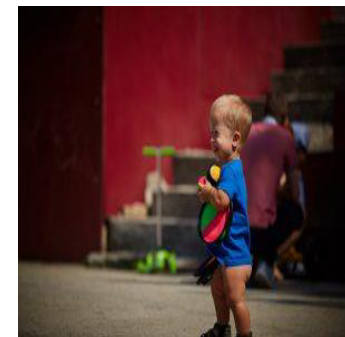


- They can meet and network with parents having kids of different age and diagnosed with Achodoplasia, who accepted their disease
- 90% of pediatricists in Slovakia deal with Achondroplasia for the first time



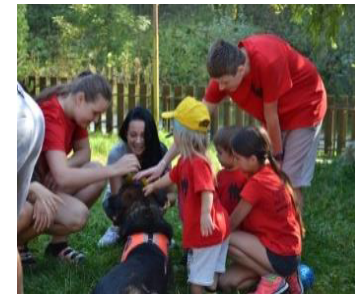
# WHAT IS ACHONDROPLASIA?

- Achondroplasia = mutation in FGFR 3 gene
- People with this disease have short stature and disproportion of arms and legs, while torso is typically normal length
- Short arms and legs = more steps, movement = more exhausted
- Premature wear of poorly developed cartilages
- Spine deformation = lower back pain, headache, leg pain
- Hydrocephalus = risk of mental disorders





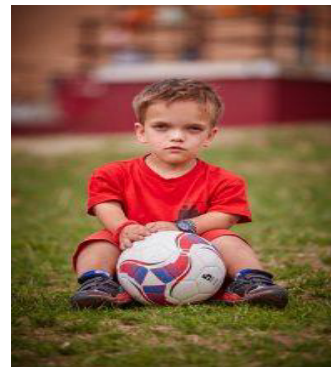
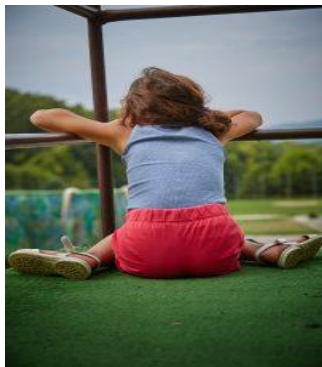
- Narrowed spinal canal = risk of paralysis, neurological diseases
- Narrowed eustachian tube = otitis media, hypoacusis
- Risk of overweight
- Cardiological problems = narrowed space for heart
- Dental deformations = problems with speech development
- Problems with handling self-service and other activities



# PROBLEMS THAT WE ENCOUNTER & „NORMAL DAY OF PALEČEK“



- I can't get to school, to a doctor or to playground without making breaks
- When taking a bus, I unwillingly „smell“ other people
- I can't step into a bus, train or I can't drive a car
- ATM's are placed too high
- I can't reach toilets and sinks



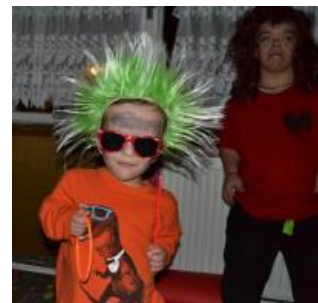
- I can take a lift only to a second floor, can't reach higher buttons
- I have to take a break when taking stairs
- I can't reach shelves in the supermarket
- I am limited when it comes to job offers
- After having a personal interview, they don't accept me
- It is hard for me to find a girlfriend/boyfriend
- I can't buy confection without further adjustments



# PROBLEMS WITH BUREAUCRACY IN SLOVAKIA = FIRST FAILURE



- **Diagnosis Achondroplasia** is defined by a height limit of **120cm!!!**
- (121cm is then a healthy person, without the right to a lifetime confirmation of a natural person with severe disabilities)
- It is assessed according to the state of health and not the inborn/imminent diagnosis



# THE ASSESSMENT FAILS ON THE STATE LEVEL

(OFFICE OF LABOUR, SOCIAL AFFAIRS AND FAMILY A SOCIAL INSURANCE)



*After calling the Ministry of Social Affairs and the Slovak Republic, negotiations were unsuccessful*

- Confirmation of a natural person with severe disabilities
- Grant for a motor vehicle, its adjustments and operations
- Grant for bathroom adjustments (toilet)
- Grant for clothes adjustments
- Confirmation of invalidity allowance
- Successful employment





# VISION, EXPECTATIONS OF HELP



- Everyone with this disease should be entitled for **confirmation of a natural person with severe disabilities with a guide and parking card**
- Creating new rules for acceptance of **confirmation of a natural person with severe disabilities in all EU countries**
- Financial support for this association – EU?
- Support a distribution of a specific medicine for this unique disease - „Modified recombinant human natriuretic type C peptide“





# WHERE IS „PALČEK“ GOING TO ?



- With increasing number of members and meeting, we would like to use media to **spread awareness** about this disease and life of little people
- Improve **fundraising** activities to support the association – cultural, social and sport activities
- Have a meeting of „Paleček“ in wellness (with rehabilitation activities to improve health conditions), or health retreat by the sea
- To address the Ministry of Health of the Slovak Republic with the request to create an specialized centre and a team of patients with Achondroplasia





**THANK YOU FOR YOUR ATTENTION**

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