Comparison between Participation and Desire to Participate in Activities Among Children with Skeletal Dysplasias

INTRODUCTION
- Osteochondrodysplasias, or skeletal dysplasias (SD), are a genetically heterogeneous group of over 400 disorders associated with abnormal bone and cartilage growth and development.
- Common symptoms of patients with various SDs include: shortening of the bones in the legs/arms, asymmetric bone growth, short stature, fragile bones and spinal stenosis.
- Because of these various orthopedic issues, affected patients’ participation in various activities can be limited.

PURPOSE
- This study aims to better understand the discrepancies between activity participation and preference in the pediatric skeletal dysplasia population.
- By identifying activities that children want to be doing, we can encourage them to participate in these activities in the future to improve their quality of life.

HYPOTHESES
We hypothesized that:
1. There are certain activities that children with SD would like to be doing, but do not participate in.
2. More male children with SD participate in physical activities than female children with SD.
3. More average-statured children with SD participate in certain activities than short-statured children with SD.

CONCLUSIONS AND SIGNIFICANCE
- Children with skeletal dysplasias participate in a wide variety of activities. However, they desire to participate in more activities than they currently do across all domains (recreational, physical, social, self-improvement and skill-based activities).
- Depending on the severity of their condition, and with the proper support, children with skeletal dysplasias could accomplish many of these desired activities.
- It is important to understand patient interests in order to recommend therapies/activities to enhance quality of life and disprove myths about limitations and/or restrictions for children with SD.

METHODS
- At the time of their visit to the Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasias, the pediatric patients were asked to complete the following two surveys:
  - Children’s Assessment of Participation and Enjoyment (CAPE) for activity participation.
  - Preferences for Activity in Children (PAC) for activity preference.
- Both questionnaires address the same recreational, physical, social, self-improvement and skill-based activity domains.
- These surveys were validated in Ontario, Canada for children (ages 6-21) with or without disabilities.

- Patient Population:
  - n=22, 7 to 21 years old
  - All races and sexes were included
  - Children diagnosed with various skeletal dysplasias

- Analysis:
  - The binary (yes/no) responses on the CAPE were converted to the PAC preference 1-3 scale in order to facilitate comparison.
  - A non-parametric Mann-Whitney U test and two chi-square analyses were conducted to analyze the data.

RESULTS
- Overall, significantly more SD children would like to be doing activities than the amount of SD children who actually participated in these activities (p<0.05).
- There was no significant difference between participation in physical activities between boys and girls.
- More average-statured SD children participated in the following activities than short-statured children with SD: doing team sports, bicycling, playing games, talking on the phone (p<0.05).

FUTURE DIRECTIONS
- Continue to analyze surveys from an increased number of participants to validate activity participation and preference.
- Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasias at Hospital for Special Surgery will host activities in areas of interest of patients.

REFERENCES