

Hudson – Overstuffing and pocketing of food in CHARGE

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- There is minimal information concerning mouth over-stuffing or pocketing of food in cheeks during eating in children/adults with CHARGE syndrome and the resulting feeding and swallowing issues

Who is eligible: parent or guardian of child

- Definite CHARGE syndrome (is your information in CSCDP?), any age
- Overstuff mouth or pocket food

How the research will be conducted at conference

Interview at the conference or on the phone and consists of 3 items:

Estimated time: 45 minutes



Mouth Over-Stuffing and Pocketing of Food in Cheeks in Children with CHARGE Syndrome

Study Description

- There is minimal information concerning mouth over-stuffing or pocketing of food in cheeks during eating in children/adults with CHARGE syndrome and the resulting feeding and swallowing issues
- This study would like to describe this phenomenon by interviewing parents of children or adults with CHARGE syndrome who have experienced these eating behaviors

Eligibility

- Parents of children or adults with a confirmed diagnosis of CHARGE syndrome who over-stuff their mouth and/or pocket food in their cheeks during meals
- No age limit on CHARGE participants

Participation

- Interview in person at the CHARGE syndrome conference or over the phone
- Interview (approx. 40-60 min) consists of:
 - o Demographics and CHARGE Syndrome Characteristics Questionnaire
 - o Feeding/Swallowing Impact Survey
 - o Pre-set questions about your child/adult experiences during meals with the following: eating, mouth over-stuffing and/or food pocketing, chewing, choking, swallowing, and therapy