

UNDERSTANDING THE VELOCARDIOFACIAL SYNDROME: A MATERIAL FOR PARENTS AND CAREGIVERS

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OBJECTIVE: Not all babies born with the velocardiofacial syndrome (VCFS) are diagnosed during the first years of life leading to late management of clinical conditions associated to this genetic disorder. The objective of this project was to develop a material to describe to parents and caregivers the most common clinical findings associated to the VCFS. **METHOD:** A literature search revealed no materials specifically prepared to guide parents of babies with VCFS in the Portuguese language. Using the list of more than 180 findings associated to the condition a material was prepared in layman's terms and was narrated in the format of an educational script. **RESULTS:** The narrated text was combined to illustration and used to create a power point material for caregivers addressing the major categories of clinical conditions reported in children with SVCF. After accessing the material the caregivers were expected to: identify clinical manifestations of VCFS; understand the importance of early identification; Identify actions that the caregiver can take to favor prevention and treatment of conditions associated to SVCF. **CONCLUSION:** The material developed is guided to help caregivers identify clinical conditions associated to SVCF and may foster early identification and adequate referral for this condition.

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