Knowledge and Self-Esteem in Individuals with Neurofibromatosis Type 1 (NF1)

Kayla Vaughn, BS (Advisor: Myla Ashfaq, MS, CGC)

Neurofibromatosis Type 1 (NF1) is a progressive genetic disorder characterized mainly by café-au-lait macules, Lisch nodules, as well as cutaneous and subcutaneous neurofibromas among other traits. Due to the physical manifestations of the condition, it has been perceived that individuals with NF1 have lower self-esteem (SE) when compared to the general population. Additionally, a study published over 20 years ago found that overall knowledge of NF1 was poor in individuals affected with the condition. The goal of our study was to reassess knowledge in this population and investigate whether it is related to SE. A survey comprised of knowledge-based questions and the Rosenberg Self-Esteem Scale was distributed to individuals with NF1 through the Texas NF Foundation. Overall, the 49 respondents (13 to 73 years old) had higher than expected knowledge of NF1 (mean score = 77.9% correct answers) across various aspects of the condition. Consistent with previous studies, the SE of our study population was lower compared to general population norms. Although there was no correlation detected between knowledge and SE, SE scores were on average higher if a person reported to have friends with NF1, attended a support group, attended a NF clinic, or received genetic counseling. All of these factors may help to reduce stigmatization felt by individuals with NF1 and may be potential avenues for developing positive coping mechanisms.

Advisory Committee:

- Myla Ashfaq, MS, CGC, Chair
- Syed Shahrulk Hashmi, MD, MPH, PhD
- Hope Northrup, MD
- Sarah Jane Noblin, MS, CGC
- John Slopis, MD