

## Overview of an international stigmatization study

Presentation Shawn Reynolds – psychologist

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Nevus Outreach Conference July 2018

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Notification: this report is based on my personal notes and pictures made from the presentation. Though I believe it's quite an accurate report of the presentation, I'm not responsible for misinterpretations or translation errors.

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Aims:

1. Assessment of quality and life and psychological adjustment in children, adolescents, and young people with CMN
2. Impact on family and experiences of parents

Method:

- Worldwide online survey (US/Canada: 94, Europe 108, Australia 15, other 18) (121 no surgery, 94 partial removal, 20 full removal)
- Parent reports for children ages 1 month-18 years
- Self-reports for adolescents and young adults ages 14-25 years

Implications:

Identity of risk and resilience for emotional problems associated with CMN.  
Provision of adequate support

Parents of children ages 1 to 12 months did not report any impairment of their child's health-related quality of life. Parents of children ages 13-21 months reported reduced emotional functioning. Parents of children ages 2-18 years reported reduced emotional, social and school functioning.

36% of parents of 2-18 years old reported clinically relevant psychosocial health problems 2x higher risk compared to population norms.

Predictors of psychological adjustment are:

Those experiencing neurological problems, skin-related discomfort (for example pain or itch) or high level levels or perceived stigmatization are particularly vulnerable to their health-related quality of life or psychological adjustment and, therefore, might need special monitoring and support.

Support should focus on management of skin-related discomfort and on coping strategies to deal with stigmatization like practicing how to respond to questions, staring, or teasing/training or social interaction skills.

We need to raise awareness about CMN to prevent stigmatization!