

**PP-159****Like or dislike? Ewing sarcoma on Facebook****P. Ruckenstein**¹, M. Schippinger², A.B. Gerwin², P. Liebmann³, A. Leithner²¹ *AKH Medical University Clinic, Vienna, Austria*² *LKH Medical University Clinic, Graz, Austria*³ *UKH Vienna/Meidling Trauma Center, Vienna, Austria*

Background: Increasing numbers of patients are raising their voice in online forums via social media platforms to exchange health related information. With more than one billion members all over the world Facebook.com is the leading social media platform including medical related issues. Ewing sarcoma mainly affects teenagers and young adults and a large part of this age group uses Facebook. However little is known about the impact of this form of communication via online platforms on Ewing sarcoma patients.

Objective: The aim of this study is to analyze Ewing sarcoma patient's and relative's behavior on Facebook.

Methods: We examined a Facebook group named "Ewing sarcoma awareness" that is used to exchange information for both, patients and relatives regarding Ewing sarcoma. A self-designed questionnaire was used to compare patient's and relative's results. Sixty-five members of the Facebook group (26 patients, 39 relatives) out of 2.227 international group members participated in our study. We also analyzed all processes (posts, likes, threads, links) in the group during 6 months.

Results: More than seventy percent of all participants reported that they use the group "Ewing sarcoma awareness" as a source of information about Ewing sarcoma. Eighty-nine percent agreed a little or a lot, that being in contact with other people affected via the group makes it easier to handle the diagnosis. Twenty percent of participants reported that the group affected their choice of treatment and in fifteen percent participants were influenced in the selection of their specialist. Over all no significant difference was found comparing patient's and relative's results. Only regarding the recommendation of the Facebook group patients achieved significant higher results. During the last 6 months most activities in the group dealt about sharing destiny and handling the diagnosis. Fundraising played a minor role.

Conclusion: The Facebook group "Ewing Sarcoma Awareness" seems to have a relevant impact for group members regarding their choice of treatment. Moreover, participants turn to the group to receive support in everyday life. Statements made in the group are in part questionable from a medical point of view and their impact on patient's care, need further evaluation.

Keywords: Social media; Facebook; Ewing sarcoma; Social media networking