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TIME FOR A CONTROLLED TRIAL OF MINOCYCLINE FOR FRAGILE X SYNDROME

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Advances in the neurobiology of Fragile X Syndrome (FXS) have lead to new targeted treatments. Minocycline, one of the tetracycline derivates, can normalize the synaptic connections in the fragile X knock out mouse by lowering matrix metalloproteinase-9 (MMP-9) levels . This is a preliminary survey to see the benefits and the side effects of minocycline treatment in children and adults with fragile X syndrome (FXS). We surveyed 50 patients (43 males, 7 females) with FXS who received minocycline treatment for at least 2 weeks. The questionnaire given to parents covers the changes in language, academic abilities, attention, behavior, physical features and side effects of minocycline treatment. The mean duration of minocycline treatment was 3.6 ± 4.6 months. Of the 50 families who were interviewed regarding treatment of their child/ family member, families reported that 74 % had improvement in at least one cognitive/behavioral area including language (54%), attention (50%), social communication (44%), academic abilities (40%) and anxiety (30%). In younger children (<8 yo), families reported a bigger improvements in attention (100%) and language (85.7%). However, we also found 14% of patients became more hyperactive, 12% demonstrated an increase in moodiness and 12% developed a sleep disturbances on minocycline treatment. There were additional side effects including loss of appetite (15.1%), gastrointestinal upset (11.3%), diarrhea (7.5%) and headache (7.5%). In conclusion, these findings suggest that there may be benefits from minocycline treatment in FXS especially in younger children. Controlled trials are needed to prove the efficacy of minocycline in those with FXS.