research on the possible treatments for 16p11.2

enhancing the need to study the community

Recent mouse studies that point to possible treatments for individuals with 16p11.2 deletions and autism are described below. While the potential treatment is exciting, there is important information that needs to be collected before human studies could begin. It is important for the natural history of 16p11.2 deletion to be well described and documented. The best way to do that is to participate in Simons VIP and the longitudinal study. Documented natural history will help researchers develop clinical endpoints that can be easily measured in a year or less.

Almost 10 years ago I started working with the Duchenne Muscular Dystrophy (DMD) community to prepare for drug trials, which are now leading to FDA approved drugs. We created www.duchenneconnect.org, an online community to begin to collect the necessary information. This early planning and participation by the families of the boys and young men with DMD allowed the drug trials to proceed. You can help pave the way for clinical trials of treatments for 16p11.2 by participating in Simons VIP now.

- Andy Faucett, M.S., SVIP