

August 2019

A brief update on the TREATWOLFRAM clinical trial.

I am pleased to say that we have now recruited over 10 participants- thank you to everyone who has taken part so far. Our first participants have reached their 6 month follow-up. I am very grateful that families are completing all their assessments. The information being collected will be incredibly helpful for the whole worldwide Wolfram community.

Our clinical trials pharmacy at St Guy's and St Thomas's hospital is packaging up the next batch of medicines to deliver to the Birmingham Children's hospital and Queen Elizabeth Hospitals sites. We anticipate the adult site opening during the next 6 weeks.

For those people who are already participating, I need to request that you **always** bring all your medicine pots and unused supplies of medicines when you come for a study visit. This is really important for the integrity of the trial; and to check that people are taking the medicine. If we have to report that people are not bringing back their empty and unused medicine containers, the trial will be criticised when we report the findings. Secondly, may I ask that when participants come for repeat vision tests, please **always** bring along your prescription glasses. This is because we are measuring best corrected vision, corrected with glasses.

I look forward to meeting some of you at the WSUK conference in September, and discussing the trial with you in more detail then.

Sincerely

Tim