

JAMES AND MATTHEW - A MUM'S STORY

Both, James and Matthew have POTS, James diagnosed and Matthew treated for but not formally diagnosed. They are currently under an Adolescent Specialist at UCLH. James will be 18 in January and he has requested to be referred to Professor Mathias in London. Our GP is particularly supportive and has been very understanding writing letters for examination dispensation and giving the boys sound advice on how to help themselves. The medication they continue to take is a beta-blocker and an isotonic fluid, daily, as prescribed in July 2008. Luckily for them this combination has alleviated the worst of their symptoms. Their quality of life has greatly improved, although, they are both still learning to pace themselves and listen to their bodies.

James is 17 years old and in Year 12 studying AS English Literature, Psychology, History and Chemistry. Despite missing nearly two years of school this did not seem to affect James' GCSE results with him achieving 2 A*'s, 8 A's and a B. He is hoping to go to University next October to study for a History degree. James has also successfully completed his Duke of Edinburgh Silver Award. The staff and his group of close friends were and are very supportive. He found the walking expeditions particularly exhausting and his friends all helped by carrying his equipment, no mean feat for them with their own. This year he has embarked on the Gold Award and is hoping to complete his expeditions, in canoes this time, during the Summer Holidays. Although he has not been able to play regular football and participate in P.E, he did pass his FA Level One Coaching Badges and trains the goal-keepers for a local U15 football team, for up to 45 minutes once a week. Over the winter he did seem particularly susceptible to colds and viruses, and two weeks would not go by without him suffering with either a sniffle or sore throat. As I write this he has overdone it in the past week and has spent the past couple of days suffering with headaches and exhaustion. He knows he just has to have complete rest for a few days and he will soon be back to school. The recent heat has been particularly draining for them both.

Matthew is now 15 years old and in Year 10 studying for his GCSE's next year. Once again despite missing school for most of year 8, it does not seem to have a detrimental effect on his studies. He is currently achieving A*'s in Science and predicted A's in most of his other subjects. Matthew has been able to participate in school P.E (apart from sprinting and running) and although it is exhausting, with him having to spend all evening resting and lying down, he greatly enjoys it. This past season he also joined a local football team as a goalkeeper. The team's manager and trainer are both understanding and allow him to train at his own pace and rest as necessary. Matthew is particularly susceptible to headaches and often takes paracetamol. He is still learning to pace himself and does get frustrated at times that he cannot do everything his friends do, but is beginning to understand his limitations. He usually has between two and five days off school each half term having to have complete rest. Matthew is also taking a long course of strong antibiotics for acne which is particularly bad on his back (which James also has but seems to be growing out of).

I hope that this update on James and Matthew's progress will give fellow sufferers some hope and show that once a suitable medicine combination is found, then the quality of life can improve, along with the understanding and support from their family, friends, school and our local GP. And with information on how they can help themselves, provided by the great work of charities such as STARS, means that they can live a reasonably full and happy life, albeit with some restrictions.

Donna Eley, July 2011