

SAB Second Meeting Report

for the

M Y R O V L Y T I S T R U S T

3rd September 2008

Present: Laura Schmidt; Eamonn Maher; Maurice van Steensel; John Solly.

Apologies: Dian Donnai

Taking minutes: JCS

Summary of Discussions:

Current MT Activities

Several grants have already been awarded, and more have been agreed in principle. The MT recently organised a small renal gene therapy meeting in London for gene therapists and kidney experts with a view to possibly funding research in this area. MT is providing some financial support for Doctors for Reform, a lobby group that aims to alter current UK legislation to allow top-up payments for drugs/treatment not currently available on the NHS. Two articles have been published introducing MT to a wider audience: one in the Genetic Interest Group's newsletter (sent to ~130 UK medical charities); one in OrphaNews Europe, the European Union's Rare Diseases Task Force newsletter (sent to ~10,000 people throughout Europe).

Planned MT Activities

There was a general discussion about the areas MT should be considering funding. This might include basic research, animal models, a rapamycin ointment clinical trial, drug development, biobanks, policy development etc. New directions are still being uncovered in terms of folliculin cell biology, so MT should consider continuing to "throw a wide net".

Next meeting date

Early March 2009.