

SAB Third Meeting Report

for the

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

16th November 2009

Present: Laura Schmidt; Eamonn Maher; Maurice van Steensel; John Solly, Duncan Azzopardi

Apologies: Dian Donnai, Terry Cook, Andrew Hopkins

Taking minutes: JCS and DLA

Summary of Discussions:

Current MT Activities

Several further grants have been awarded since the last meeting, including:

1. Three renal gene therapy grants to: Richard Harbottle; Yosef Haviv; collaboration between Andy Baker and David Curiel/Justin Roth.
2. Three pilot grants, with Partnership for Cures and Bruce Bloom, for drug repurposing.
3. Grants to Maria Czyzyk-Krzeska and Vera Krymskaya.

MT would like there to be some patient voice for BHD. Since the BHDFEA is stepping back slightly, at least for the moment, MT is considering seeing if patients or family members might be interested in being part of a patient group. www.BHDSyndrome.org continues to develop – research tools, forum etc.

Planned MT Activities

There was a general discussion about areas MT could consider funding. These might include lung work, extending existing grants, drug development, more animal models, encouraging greater collaboration and sharing of resources, and more general rare disease support.

Second BHD Symposium

The hotel and conference venue have been booked for 22nd April 2010. There was a general discussion about logistics, including: registration website; scientific committee; deadline for submitting poster abstracts; possible patient involvement

Next meeting date

22nd April 2010, Washington DC