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THE MULTIDISCIPLINARY ADULT ATAXIA TELANGIECTASIA SERVICE

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Background Ataxia Telangiectasia (AT) is a rare progressive neurodegenerative disorder with no proven interventions to prevent or delay disease progression. Papworth Hospital NHS Foundation Trust is nationally commissioned to provide an annual multidisciplinary team (MDT) review for adult patients with AT following on from their paediatric care.

Methods We conducted a retrospective evaluation of patients seen between May and November 2013 specifically assessing the outcomes of MDT discussion for each patient and new recommendations made to local healthcare providers following a 36-hour admission for annual review. The MDT consisted of a neurologist, respiratory physician, immunologist, physiotherapist, occupational therapist (OT), social worker (SW) and speech and language therapist.

Results Seventeen patients (3 new/14 follow-up) were assessed. A minimum of six out of seven MDT members attended meetings. A total of 65 new recommendations were made. All members of the team contributed with the most recommendations provided by OT and SW. Examples of recommendations include: optimisation of home ergonomics, initiation of anti-depressants and botox for dystonia.

Conclusion In a rare degenerative neurological condition re-evaluation by a specialist MDT, whilst not affecting disease progression, leads to novel interventions to improve patient care.