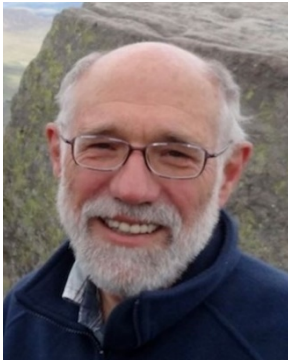


UK-Association for Glycogen Storage Disease (Bristol, UK)



Andrew Wakelin

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Biosketch

Andrew was diagnosed with McArdle disease in 1980. He recalls symptoms from age 4, but at 16 after four misdiagnoses he gave up seeking answers. Then at age 30, a rheumatologist investigating his gout listened to his history, did a CK test and referred him to a neurologist. He had a muscle biopsy and at last there was a diagnosis. 20 years later it was confirmed by genetic testing.

Andrew discovered the McArdle Clinic in 1999, then operating three afternoons per year. He began to assist other patients and in 2004 he took on the voluntary role of AGSD-UK McArdle's coordinator. He began analysing what he had done and how he managed – culminating in the "101 Tips" book, the "Medical Overview" booklet and other advice to patients. He has developed practical residential courses which have been attended by people from 17 countries. He has met over 500 McArdle people and has assisted patients, doctors and researchers around the world to better understand the condition.

A graphic designer by training, Andrew ran his own design company for 25 years, then a software development company. He has served as a trustee and chairman in local, national and international non-profit organisations, including AGSD-UK.

In 2012 Andrew became a patient representative and board member on Euromac, with responsibility for the dissemination work package.