

## Election of Ataxia UK Trustees 2021

<p><b>Mark Deere</b></p> <p>(Diagnosed with SCA28 in 2019)</p>	<p><b>Why do you want to become a Trustee of Ataxia UK?</b></p> <p>I am sure those who have worked with me would describe me as being honest, fair, demanding and keen to do the right thing. Having spent about 35 years learning and practicing abilities that I would still like to use (and only a strained voice prevents me from doing so in hotels), I want to now use them to assist an organization that has facilitated my time back in the UK. I would be keen to shape the work and strategic direction of the charity and my previous experience of setting and evaluating the strategic vision of the Hotels I worked for would help this. My knowledge of revenue-generation and cost-containment would be beneficial, and my previous need for consideration of the reputation of an organization - having the systems and processes in place to ensure the overall direction, effectiveness, supervision and accountability were to a high standard, would assist in good governance. I have exercised good judgement in the past - shown by the success of these businesses, and have had to be logical, organized and creative to thrive - I would bring these things to the Ataxia UK Board, as well as a keen willingness to devote the time and effort required to fulfil the role and have a proven track-record of speaking up in situations involving many different cultures and backgrounds. I would also like to help in raising awareness of Ataxia and feel that my previous roles working closely with the respective marketing teams, would help in this.</p>
	<p><b>How do you think your skills and experience would enable you to fulfil the role of a Trustee?</b></p> <p>I believe that the skills and experience I utilised in my career would enable me to carry out requirements of a trustee. My roles as a Hotel Manager mirror many of the statutory duties of a trustee – complying with and following goals and laws, the effective use of available resources (e.g. Manpower, equipment and of course, money), the giving of strategic direction (I had to do this annually – with the objectives of fourteen departments all fitting in with the Hotel, and company strategic objectives set) and ensuring the good name of the organisation was safeguarded (by the way everything was done – with integrity). The generation of cost-saving and revenue-generating ideas was also a key feature, and the creation of groups and committees to generate these ideas was a necessity, such as is my last role we established a quality committee and a weekly revenue meeting – both to review where we were and brainstorm ideas to</p>

implement moving forward. I was also required to scrutinise memos, directions, papers, and the financials of the Hotel (monthly, quarterly and annually) and also to prioritise what to do and when. A great example of the need to represent the Hotel/company in a professional way was me sitting on the DCTM (the Dubai Tourism and Marketing) Hotels committee, which was a Dubai Government initiative to steer the strategy of Dubai with regards to hotels. A lot of the requirements of a trustee are thus very well known to me.

<p><b>Angela Hosie</b></p> <p>(diagnosed with ataxia in 2011)</p>	<p><b>Why do you want to become a Trustee of Ataxia UK?</b></p> <p>Being a trustee is a challenging role - and rightly so given the responsibilities of the Board - but also hugely rewarding role and I want to use the impetus and experience I have to make a difference to others. That is important to me. It's a cliché but Ataxia has changed my life. Moving forward with a life-changing diagnosis is tough, but when that condition is rare and so few people (some healthcare professionals included) have heard of the condition and have any awareness of its effects - it all combines to make adjusting to that reality even more difficult. I have enjoyed becoming more involved with Ataxia UK in the past year. I first learnt of Ataxia UK ten years ago after my diagnosis, but it is in the last year that my family and work commitments have changed allowing me the time to become more involved and engaged in activities; initially with the excellent virtual activities the IN-Control team have run and then latterly with engagement in two of the Ataxia UK steering groups. I see being a trustee as a vital and stimulating role, ensuring the charity is not only reaching its goals, but is forward-thinking and creative to run as efficiently as possible. The prospect of working with Ataxia UK, UK - working amongst like-minded individuals at the very heart of the charity and its work, increasing awareness and striving to find treatments or cures - is an invigorating prospect. It is nothing less than a fantastic opportunity to help the ataxia community.</p>
	<p><b>How do you think your skills and experience would enable you to fulfil the role of a Trustee?</b></p> <p>I have a broad range of skills and experience to bring to the trustee role. I worked latterly as Project Manager for 10 years with a placement agent; a robust compliance environment requiring determined and disciplined planning with an eye for detail and accuracy. Prior to this I worked in public service. For many years in the constituency office of a local MP Phil Willis as his administrator and his assistant caseworker, liaising with government departments, local authorities,</p>

and the voluntary sector on behalf of constituents; additionally working on election campaigns, including General Elections. I previously served with the Diplomatic Service for several years including postings to High Commissions in India and Ghana. For several years I have been a school governor – this provides familiarity with the strategic role of the Board working closely with leadership and SMT. I sit on the Head’s appraisal committee and regularly sit on staff recruitment panels, and on disciplinary panels on the rare instances these are needed. I am also link governor for Health and Safety, a role with statutory responsibilities and a role which since the arrival of Covid-19 across the world, has expanded significantly through developing new strategies and policies in a constantly changing environment with ever-changing resource levels. I view the relationship between board and charity leadership/SMT being that of a ‘critical friend’ – to support and work collaboratively through honest, independent judgement whilst embracing creativity and working in a future-forward manner to achieve the charity’s vision and mission.

<p><b>Rachel Harrison</b></p> <p>(Diagnosed with ataxia in 1997)</p>	<p><b>Why do you want to become a Trustee of Ataxia UK?</b></p> <p>In the past I have undertaken many roles where I have learned I enjoy putting my own experience towards projects which benefit a much wider group of people. I enjoy listening to other people’s point of view and understand that we all want/need different things; collating different viewpoints to reach a consensus decision to improve outcomes for everyone. I have set up and maintain my own home and support. I have successfully developed skills to navigate the benefit system, disability facilities grants, wheelchair services, social services and more. Under the direct payments scheme I have employed personal assistants for 20 years. I now employ a small part time team; this enables me to live independently on my own with my life under my control. In turn this enables me to have ‘normal’ relationships with my friends and family. I feel empowered and able to advocate for myself; I have a quality of life I would like to help others achieve. Working with a group of people towards common objectives is something I enjoy and am good at. I have worked in several user-led organisations alongside people with varied impairments including sensory loss, learning disability and autism. These organisations have different priorities around disability rights, independent living, and access to buildings at design stage. The reason I haven’t applied before is the energy required to get to physical meetings but in this covid/virtual world opportunities are much less limited.</p>
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**How do you think your skills and experience would enable you to fulfil the role of a Trustee?**

**Since graduating with a BSc from the University of Southampton in Mathematics in 2001 I have gained a variety of experience in unpaid roles: - I was chair of governors at my local primary school for 8 years as a community governor. Within this role I partook in training including safer recruitment, safeguarding and financial planning. I took part in 3 Ofsted inspections and learned the importance of good governance; reading and ensuring all paperwork is understood, separating strategic from operational matters, monitoring the impact of policies and triangulating evidence. I am co-chair of the Personalisation Expert Panel which is a group of service users who work as a critical friend to Hampshire County Council Adult Health & Care Departmental management team. We hold frequent meetings with the director and/or assistant directors engaging in strategic level coproduction. Alongside these meetings I sit on the Direct Payments Board; during Covid I have been instrumental in setting up regular contact with individual employers, getting PAs to come forward for the vaccine and setting up systems for the distribution of PPE. I am part of a Patient and Public Involvement strategic group for the School of Health Sciences at the University of Southampton and also take part in lecturing to students. Our wheelchair services were struggling and after taking part in a review I was invited to join staff from WCS, referring OTs, a member of MND staff and CCG staff to undertake a Quality Improvement fellowship run by Health Education England which 8 of us completed over a year.**