

Chair profile Questions

1. What attracted you to becoming a chair?

I 'fell' into the job in May 2006 without really thinking what I was doing, and without knowing much about what the job of 'chair' entails at all - it's probably just as well because I'm not sure that many people in a new charity really comprehend this either, or how much it will take over their lives!

2. Which organisation do you work with?

I am chair of the Association for Multiple Endocrine Neoplasia Disorders (AMEND) which became a registered charity in 2002. We support and provide information to patients, families and carers affected by the rare genetic conditions called MEN, where sufferers develop various tumours of a variety of endocrine glands in the body, some cancerous, some occurring in childhood, and others just plain dangerous.

As often happens with smaller charities like ours (8 trustees, 84 patient members), the trustees actually do all the work. We have no paid staff; we are all volunteers, and we have no premises or big budgets; we work from home (or work) on our own computers in our own time. We are still learning to make the differentiation between our dual roles; that of 'staff' and trustee, and sometimes, quite frankly, it is impossible.

3. How did you become chair of AMEND?

I contacted the original chair (who, thank goodness, is still a trustee) right back at the start of AMEND's formation in 2001, and, together with my mother, volunteered to help out with the hard graft in order to eventually be able to be in contact with others suffering from our type of the disorder. I had never done anything like this before (my background is in investment banking administration and child-rearing!), but the work was so close to my heart and the disease that affects me and other members of my family, that I quickly became hooked on helping other patients avoid some of the experiences I had gone through during the previous few years, and learning as much about the disease from the relatively few UK specialists that treat it. After some time, it was clear that the amount of work involved as the charity had grown, was growing in proportion, and the original chair stepped down. No-one else seemed keen to take on the role and so, because of the immense 'job satisfaction' I get from working for the charity, I put myself forward and was voted in at the 2006 AGM. Of course, my husband thinks I'm just trying to avoid getting back out into the paid job market!

4. Is there anything that would make you an even more effective chair?

My children and I are big Harry Potter fans and the immediate thing that springs to mind is Hermione Granger's Time-Turner so that I can be in 2 places at once! I could also do with a house elf or two to do all those mundane chores that get put on hold as I squirrel myself away in my study (cupboard) on my

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laptop. But back in the real world, just a 'fount of all knowledge' would be great.

5. What's the biggest challenge you have faced in your role?

There have been a couple of challenges, the first of which was being contacted by the Charity Commission within weeks of becoming chair to have our trustee recruitment process audited (as part of a random audit of 500 charities). Thankfully with a little deadline negotiation we managed to look at and adjust our processes (which to that point I hadn't had a chance to address) and thereafter complete the audit in time.

The second challenge occurred earlier this year when I had to have surgery to remove and replace a cancerous shoulder bone. There was (and still is) so much going on with the charity that it was very hard to let go. I knew that I would be unable to sit at the laptop and type anything for weeks and that I was going to miss one of the biggest medical conferences of the year, as well as an important meeting. The laptop challenge was solved by buying dictation software, although some assumed spellings were quite hilarious, and it got rather frustrating having to constantly explain why it was that I could send emails. As for the important meeting, I managed to persuade the attendees to have me 'patched in' from my hospital bed. Apparently I was asked a couple of questions half way through the two-hour meeting but had succumbed to the morphine drip by then! It did teach me that the wheels would still turn without me around for a while, and that was quite humbling, as well as reassuring.

6. What is the major area of work or issue that you are facing now as chair?

We currently have two major areas of work that require addressing: Firstly, persuading my fellow trustees to sit down together to develop some sort of Strategic Plan. We suffer badly from wide geographic spread (as well as MEN!) and have 3 doctors on the committee - tying everyone down is a nightmare. I am looking for a virtual/USB/MS compatible whip! Until then, I am investigating conference calling. Secondly, we have brought a large team of UK specialists together to look at finding ways of improving the care and management of UK MEN patients. Again, tying people down is difficult, and negotiating the twists and turns of government and the NHS is not for the faint-hearted. The learning curve just keeps on getting steeper.

7. What do you consider the most satisfying aspect of your role as chair?

Every so often a card drops onto the doormat or I get an email saying 'thank you so much for all your help', and it makes me go all warm and fuzzy, and sometimes even a little tearful! When I meet the patients we help at our AGM and Information Afternoon or on other occasions, I get an enormous amount of satisfaction from talking to them and being able to empathize with them. I imagine that is harder for chairs of larger charities to feel so connected at

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'grass roots' level, and if that ever changed for me, I would no longer be happy doing the job.

8. What do you think is the ideal term of office that a chair should serve?

1 year hardly gives anyone time to get their teeth into things, and 4 can seem daunting, so probably somewhere in between, and being rather partial to even numbers, I would vote for 2 years.

9. What tips would you give to a new chair?

A lot of the work of a chair is common sense, but a certain amount of learning is necessary. Regular referral to the Charity Commission, NCVO and CTN websites is obligatory. Learn to love making lists and setting deadlines, and follow up on them!

10. If you weren't a chair/trustee, what would you do with that time?

My husband would shout, 'get a paid job!' I really should spend much more time at the gym and the pool to help my physiotherapy along the way, and to generally get fit. I am also currently a rather ineffective primary school governor and so would be able to spend much more time giving that the input it deserves. Ultimately, though, I suppose I'd have to re-enter the job market in some capacity, though the sort of job satisfaction I have now would be very hard to find!

11. As a Chair, do you welcome feedback from your staff and fellow trustees?

Most of my fellow trustees are good with feedback on issues and projects, and you do get to know who is best suited to, and therefore more likely to reply to something specific. Feedback is certainly welcome and is relatively easy as most of our correspondence is done by email (it's very hard to get hold of doctors when they're constantly in clinic, operating theatres etc!). People are a little braver in what they say by email so it's not often that I have to hound people for responses. I have had to get used to people telling me that an idea I've had is not such a good one, but that's been part of my personal learning curve, and I don't bear grudges for too long! In fact we all get along very well and our meetings, although generally long and tiring, can be quite enjoyable as well.

12. Is there any particular publication, course or resource that you have found helpful and would recommend to other chairs?

My favourite publication to date is the NCVOs 'Advice, Information, Support' book. It is very petite book for the price (£15), but it is absolutely packed

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with 'key resources for small voluntary and community organisations', and is quick and easy to refer to.