

Chairman: Raj Mahapatra Treasurer: Danny McFarlane Chief Executive: Dr Dale Webb

# National Axial Spondyloarthritis Society Trustee Elections, June 13, 2020

### 1. Dr Jackie Harris

Retired Pharmaceutical Director with long standing interest in AS.

Director of Hospital Products at Schering Plough, responsible for launch of Remicade. Director of Immunology at Abbott/Abbvie, responsible for launch of Humira. I worked closely with NASS during my working life and have always admired their programme of activities that have such a strong patient focus.

I now also have a personal interest in AS as my son was diagnosed with the condition in 2018 and I have learnt that I am a carrier of HLAB27. My admiration for the work NASS do is now even greater as I have used the helpline and pamphlets as a parent and have found these to be outstanding.

From both a professional (scientific) and personal perspective, I have a strong desire to contribute to the future success of NASS and so I would really like to be considered for a trustee role. I hope that my strategic business /sales and marketing and scientific background might be considered of use to the board of trustees if I were to be considered for this opportunity.

I have previously been a trustee at The British Tinnitus Association (4 years) and at NRAS (two years).

# 2. Raj Mahapatra

It's been my privilege to serve as trustee and Chair of NASS since 2014 and I can safely say that I have loved (almost!) every second. In that time I've worked with two Chief Executives, first Debbie and now Dale, their wonderful teams and our fabulous trustees to represent those living with AS. Two highlights have been overseeing the adoption of the NICE clinical guideline on the diagnosis and management of spondyloarthritis and the creation of the first ever All Party Parliamentary Group on axial SpA (AS) with the specific remit of ensuring the guideline's implementation.

My mission has always been to champion those who live with chronic pain for years like I did, without the explanation given by a diagnosis. It's been a source of pride that I have been invited to talk on the global stage about what it means to have AS and to continue being welcomed onto steering committees for national and international projects that have relevance to not only those with AS but also those treating it - both healthcare professionals and pharmaceutical companies.

I know that NASS changes lives. It continues to be my joy to play my part and to serve as a trustee.

#### 3. Frances Reid

NASS has become a trusted advisor to me in the year since my delayed diagnosis. I believe I can help strengthen the charity, but I also understand what it's like to be challenged by this disease. I'm about to try my second biologic.

Working for the World Ovarian Cancer Coalition I lead their global patient experience study and charter. This follows work as co-founder and Director of Public Affairs and Services of Target Ovarian Cancer (2008-2014), establishing a successful All Party Parliamentary Group driving changes in national guidance and access to diagnostics, and developing award winning support services and health professional education. I thrived on great relationships with patients, trustees, clinicians, policy makers and politicians alike, and am extremely passionate about how patient and clinical voices can influence change.

I'm an effective communicator, not just on a podium or in front of cameras but with all sorts of people, building on 13 years of experience as a programme maker for the BBC. I have worked closely with strong boards of trustees for 17 years developing and delivering successful strategies. I also ran a micro-bakery till my AS said 'no'...but I hope you'll say 'yes' to me becoming a NASS trustee!

## 4. Megan Smith

I am a positive and determined individual who is passionate about supporting people who live with axial SpA (AS). As a trustee, I would strive to inspire and empower individuals, using my personal AS journey to provide a voice for young people at the heart of NASS.

I am a dedicated NASS member, keen advocate and fundraiser. I am proud to feature and share my journey of living with fatigue in the new guides, as well as being part of the APPG for Axial Spondyloarthritis.

I have a strong background in project managing youth engagement and education programmes in schools and communities. I work as a Sports Consultant, driving global social impact through education, by developing strategies and programmes for major sporting events and governing bodies, helping clients to improve the lives of young people.

Every day people face challenges of living with AS, and NASS are always there to provide support, raise awareness and promote best practice. I want to be a trustee to support NASS in ensuring that every person with AS receives timely diagnosis and effective treatment and care, is empowered to take decisions about their health, and feels part of a supportive AS community.