

**Minutes of the 43rd Annual General Meeting
of the National Ankylosing Spondylitis Society (NASS)
on 8 June 2019 at the National Conference Centre, Solihull**

1. Raj Mahapatra was appointed Chairman of the meeting. [R(1)]
2. The Minutes of the 42nd Annual General Meeting were approved and signed as a correct record. [R(4)]
3. Report of the Honorary Chairman.
2018 was very good year for NASS. Last year we reported that the trustees had approved a growth plan from the new CEO in order to achieve our ambitious goals. They also approved a new vision statement and set of interim strategic objectives to drive our work. New staff roles have been created and recruited to, and the organisation's governance, policies and procedures have been strengthened. In 2018 we undertook all of the preparatory work for the launch of our *Every Patient Every Time* initiative, including the creation of the first ever parliamentary committee to look at the quality of care for people with axial SpA (AS), and securing sponsorship for a major programme to improve the quality of care. We developed new ways to reach out to people living with axial SpA (AS), including our *NASS Voices* conferences across the UK, and a new website.

Our business plan for 2019 commits us to new research studies, including one to develop a rigorous concept of what high quality care looks like in axial SpA (AS) from a patient perspective, and a study to understand the full economic impact of a delayed diagnosis. We are committed to the rental of an office in Hammersmith to September 2022. With a growing team we have needed to secure a second office, and are about to sign a 3 ½ year lease on a second office in Hammersmith. In autumn 2022 the leases on both premises will have expired and we will be looking for a new office able to accommodate all of the staff. For the second year we have produced an Annual Review.

4. Election to the Council of Management
 - (a) Raj Mahapatra was re-elected as Honorary Chairman. [F]
 - (b) Danny McFarlane was elected as Honorary Treasurer *in absentia*. [F]
 - (c) Nominations for ordinary members of the Council of Management.

In the meeting notice we stated,

“Retiring by rotation at the end of this meeting are Raj Mahapatra and Prof. Karl Gaffney. However, if the AGM approves Resolutions 2 and 3, then the existing Society will be wound up over the next few months and its assets transferred to the new CIO. In other words, any new trustee elected to the current Society would be a trustee for only a few months.

Therefore, the Council of Management proposes that Raj Mahapatra and Prof. Karl Gaffney be re-elected and, in the circumstances, recommends that no new nominations for election to the Council of Management be made.”

No other nominations were received, so Raj Mahapatra and Karl Gaffney are re-elected as trustees.

5. Appointments of any co-opted members to the Council of Management [G(1&2) & J]
No members were co-opted.
6. Report and confirmation of the Appointments of President, Vice-presidents and Patrons (Clause P(4))
No new appointments were made.
7. Report of the CEO in lieu of the Honorary Treasurer and presentation of the accounts year ended 31 December 2018.

NASS’s financial position strengthened further in 2018 and we continue to be a going concern. We have reserves of £1.9m (up from £1.7m in 21017). In 2018 we had income of £929,148 and expenditure of £698,680.

We continue to maximise liquidity in interest-bearing banks. Trustees approved an investments strategy in September 2018, including a Statement of Investment Principles which is a requirement of the Charity Commission. We agreed to sell four statues gifted to us by the late Dame Elisabeth Frink and have received permission from the commercial executor of the Frink estate to do so. We intend to sell one a year for four years and may use the funds to create awards in Dame Elisabeth’s name. Trustees also agreed to maximise interest on our cash via cash management providers which we will appoint in the second half of 2019.

The CEO thanked the Honorary Treasurer for developing our investment strategy, managing the work with Christie’s auction house and potential cash management providers, and for supporting our work to secure a second premises for NASS.

The auditors have provided their report on the management of NASS finances. This was the most positive report with only two small areas of note, both of which have been actioned. They had no concerns about our internal controls or processes. The CEO thanked Justyna Potiopa, Finance and Administration Manager, who has worked hard to strengthen our financial management.

8. The accounts for the period 1 January 2017 to 31 December 2017 were adopted unanimously. [P(3)]
9. Felton Pumphrey were re-appointed as auditors. [P(6)]
10. Report of the Chief Executive.

The CEO echoed the Chairman’s remarks about 2018.

Visibility of NASS is high. We have engaged people with AS through our *NASS Voices* conferences, branch visits, member surveys, social media work and our new website. We collaborate with a wide of health care professionals, talk about NASS at professional development meetings and conferences and are forging new relationships through our NASS Allies programme.

A very significant success is that we have created the first ever parliamentary committee on AS. It was launched at the House of Commons in December and will create national oversight in England of the NICE guidelines and Quality Standard on AS.

Membership numbers are up for the first time in 5 years. Between 2014 and September 2019 we lost 761 (19%) members (a drop from 3,994 to 3,233). In the last 9 months we have welcomed 318 new members, recovering 42% of those lost in the previous 5 years.

The CEO then introduced each member of staff to the AGM and thanked them for their work. The AGM gave a round of applause to the staff.

The Chairman invited the trustees to join him at the front of the room. He then explained the reasoning behind the three resolutions on which the AGM would be asked to vote. He described the evolving medical terminology used to describe the condition, the opportunities that it creates and the need for NASS to reflect that in our name. He described the reasons for proposing that NASS becomes a Charitable Incorporated Organisation, the principal benefit being that member liability would be reduced to zero.

Following questions and comments from the floor, the three resolutions were put to the vote.

11. Resolution 1: "The new Charitable Incorporated Organisation ("CIO") established or to be established by the Trustees of the Society will be named "National Axial Spondyloarthritis Society"."
The meeting voted unanimously in favour of the resolution – resolution approved. (Clause R(3))
12. Resolution 2: "The Trustees of the Society be authorised to transfer all assets of the Society remaining after the satisfaction of any proper debts and liabilities of the Society to the new CIO being a charitable organisation having objects similar to the objects of the Society and to take such steps as they consider necessary or desirable to give effect to such transfer." **The meeting voted unanimously in favour of the resolution – resolution approved.** (Clause U)
13. Resolution 3: "Following the transfer of assets referred to in Resolution 2, the Society be dissolved at such time as the Trustees of the Society deem fit, and the members' membership of it shall cease on such dissolution, and the Trustees of the Society be authorised to take such steps as they consider necessary or desirable to give effect to such dissolution." **The meeting voted unanimously in favour of the resolution – resolution approved.** (Clause U)
14. Any other business.
A member asked why NASS branch officers need to be members. The CEO explained that branch officers are quasi-officials of NASS and need to be members in order to be covered by our personal liability insurance.

A member reflected on our membership numbers in light of the estimated 200,000 people in the UK living with AS. The CEO replied that we have started the process of increasing our membership numbers and that our plans for increased awareness of AS should help to increase membership.

A member asked about our work to engage rheumatologists. The CEO described the range of our activities and plans for the future including the Aspiring to Excellence programme.

A member asked us to make clear to branches that the provision of hydrotherapy at our branches is open to everyone with axial Spondyloarthritis, not just those with Ankylosing Spondylitis.

The meeting acknowledged the support and contributions of the five trustees who had stood down at the AGM and thanked them for their service – Claire Harris, Dr. Andrew Keat, Ruth Miller, Jean Morton and Peter Wheatley-Price.

15. The date of the next AGM was provisionally agreed as Saturday 7 June. Venue to be confirmed[P(1)]

Minutes approved: September 14th, 2019

Signed by: Raj Mahapatra, Chair

