Inflammatory Neuropathies UK

Inflammatory Neuropathies UK Annual General Meeting

Saturday 3rd October 2026

Minutes

The 2026 AGM was held at the Watershed in Bristol, and online. The meeting began at 11am.

Attendees

Trustees – Carol Hooper, Lora Barclay, Nalin Sharma, Sean Austin, Stephanie Parker

Staff – Rich Collins, Tansy Miller, Claire Laird, Andrew Florence

Members, Volunteers, and members of the Community – We were joined by around 30 members of the Inflammatory Neuropathies Community

Welcome and Introductions

Carol Hooper (CH) officially started the meeting and laid out the agenda for the day. She asked all of the Trustees present to introduce themselves.

CH also welcomed our founder Glennys Sanders to the meeting (online), as well as our two Patrons Sir Ian Macfayden and Professor Richard Hughes (online). CH welcomed everyone in attendance both in the room and online.

Review of the Year

Rich Collins (RC) gave his review of the year, highlighting that this was his third AGM as Chief Executive. He outlined another amazing year for the

charity, that had been full of growth and development. The name change and rebranding had a significant impact in terms of reach and engagement. He mentioned that his biggest takeaway had been that by working with our community, we can do anything.

RC went on to talk about people remaining at the centre of what we do, how our community is everything, what the charity does to listen and how people's voices shape what we do. He highlighted that we listen, change and improve, updating services to meet needs and demands, and amplifying voices. He was proud that we had supported more people and did it better, that our financial position has improved again, and that our reach and profile is better.

He went on to say that we aren't stopping yet, and have further aspirations to improve.

Annual Report

CH gave a summary of the Trustees Report. 2025/26 had been another successful year for the charity. We reached and supported more people, and supported in more targeted ways. We had built on the foundations of GAIN and were delivering against our aims, objectives, and strategy.

CH ran through the impact report that had been published earlier this year, and the figures highlighted in the Trustees Annual Report highlighting the significant increases in the number of people supported, increases in personal grants and direct support activities, social media and website impact, and feedback from the community.

CH talked about our primary role being to support people, and how we continued to strive to reach more people so we could support more people, through an improved offer. She emphasised that it was not all just about numbers, but also about doing what we do well, and making a difference.

She highlighted our investment in research, how we worked around clinical trials, and work involving responding to consultations, helping to shape the future. She also talked about the importance of marketing and

engagement in helping us to raise awareness and advocate on behalf of the community. She was delighted that we now have a seat around the table for the most important discussions.

She also talked about the future, with a focus on delivering against our strategy, improving information, building on Local Get Togethers and Local Champions, supporting more research, and further improving reach and engagement.

Annual Accounts

Sean Ausin (SA) presented the annual accounts for the period 1st April 2025 to 31 March 202. He spoke about income for the year which had been £510,468, and was made up of donations (£133,990), fundraising (£1,333), legacies (£352,379), investment income (£13,792), grants (£5,000) and sales (£3,004).

The expenditure for the year had been £286,760, meaning that the charity had gained £250,481 in the year, which was significantly more than predicted. The charity's largest outgoings were staff (£129,456), research grants (£25,000), personal grants (£24,991), and legal and professional fees (£13,405).

Our final position was that at the end of 2025/26 we had assets of £1,243,060, made up of fixed assets (£455,868) and net assets (£797,192).

SA asked for any questions, of which there were none.

Voting

RC led the voting on the motions. He explained that papers had been circulated in advance to Voting Members, and people had already had the chance to vote online or via post. These votes had been checked and collated. He stated that he would go through the motions to be voted on, but these could only be voted on by Voting Members who had not already voted online or by post. All votes would be collated and reported within the minutes.

Annual Report, Annual Accounts, and Independent Accountants

RC led the voting on the first three motions associated with the annual report, annual accounts, and independent examiners.

Motion 1 – That the annual report for the period 1st April 2025 to 31 March 2026 be adopted

For – 29
Against – 0
Abstaining – 0

Motion carried, and the annual report for the period 1st April 2025 to 31 March 2026 was adopted.

Motion 2 – That the annual accounts for the period 1st April 2025 to 31 March 2026 be adopted

For – 24
Against – 0
Abstaining – 2

Motion carried, and the annual accounts for the period 1st April 2025 to 31 March 2026 was adopted.

Motion 3 – That Moore Thompson LLP of Bank House, Broad Street, Spalding, PE11 1TB be appointed as independent examiners for the period 1st April 2026 to 31 March 2027

For – 29
Against – 0
Abstaining – 0

Motion carried, and Moore Thompson LLP were appointed as independent examiners for the period 1st April 2026 to 31 March 2027.

Prior to the vote, Ian Macfayden asked if how long Moore Thompson had been used by the charity, and if we had put the contract to competition. RC responded that this would be the third year, that we had gone for 3 quotes prior to awarding, and that we would do the same again next year.

Trustee Appointments

RC outlined that at present we have eight Trustees. There have been no resignations over the year, but as two Trustees had reached their maximum terms at the last AGM, two new Trustees (Derren Saunders and Nalin Sharma) had been co-opted onto the Board. The Inflammatory Neuropathies UK constitution states that they both have to retire at the AGM, and they will be seeking election to the Board for the first time. Due to the rules of the constitution, one third of Trustees need to retire at each AGM. At the point we calculated this we only had 7 Trustees, so two would need to retire. This year Carol Hooper and Stephanie Parker retired from the Board. Both were seeking re-election.

RC gave a brief insight and pen picture for all Trustees seeking re-election or election.

Motion 4 – To re-elect Carol Hooper to the Board

For – 27
Against – 0
Abstaining – 0

Motion carried, and Carol Hooper was duly re-elected to the Board.

Motion 5 – To re-elect Stephanie Parker to the Board

For – 29
Against – 0
Abstaining – 0

Motion carried, and Stephanie Parker was duly re-elected to the Board.

Motion 6 – To elect Derren Saunders to the Board

For – 30
Against – 0
Abstaining – 0

Motion carried, and Derren Saunders was duly elected to the Board.

Motion 7 – To elect Nalin Sharma to the Board

For – 29
Against – 0
Abstaining – 0

Motion carried, and Nalin Sharma was duly elected to the Board.

Open Forum

RC opened the floor for any questions, queries, or comments.

1. RC was asked what his favourite part of the role was. He responded that it was linked to these events where we could get everyone together.
2. We were asked about challenges for the year. RC answered that the immediate challenge was replacing Tansy as she was due to leave us imminently. This will leave us with a significant gap in staffing which we hope to fill rapidly. But outside of that, the biggest issues remain around reaching more people. Data across the system is poor, but we do have prevalence data which says how many people with Inflammatory Neuropathies there should be in the UK. We can match that with data we hold, and this shows a significant difference in numbers of people with a condition, and the number known to us. We need to both improve our data, and reach more people. Most people impacted by an Inflammatory Neuropathy have not heard of or do not interact with the charity. We need to change this and also

reach a wider group to inform about the conditions and raise awareness.

3. RC was asked about how international links lead to benefits for the charity, the community, and to research. RC emphasised the links we have with GBS/CIDP Foundation International, EPODIN, and the Peripheral Nerve Society. These links help us to be part of and be aware of international pieces of work and research. RC highlighted the international social research done jointly with the Foundation, the white paper produced by EPODIN that we supported and helped launch at the European parliament, the international CIDP Principles of Care work which RC sits on the steering group, and the work done at the PNS to bring people to the centre of the international conference (RC facilitated the first patient meeting). These both raise the profile of the charity, but also place us at the centre of research and development, meaning we can amplify community voices around the world, and also be part of work that we can report back on and which will benefit our community.
4. We were asked about research spend and where we would invest and in what. RC built on SA's early comments that we didn't want to waste money, and that we needed to ensure that what we were investing in was worthwhile, impactful, sensible for the Charity, linked to the community's views and wishes, and affordable. Previous investments had been targeted, and current investment was well thought through. RC announced that we were investing in a PhD at Exeter University over the next two years which was focussed on looking at impacts and burden of Inflammatory Neuropathies. He also announced a two-year investment in new international guidelines around Vasculitic Neuropathies with the Peripheral Nerve Society. The Charity is working on new research strategy that will guide investment in the future, and in the meantime the Board had discussed approaches (particularly around investment in people and fellowships) and would still consider all approaches that were made to the charity.

Thanking Individuals

CH thanked all of the staff, volunteers, trustees, members, founder, and patrons for their support.

Finally, CH thanked everyone for attending.

Any Other Business

There were no further items of business.

The AGM closed at 12.00pm.