

BOARD MEETING

Saturday 14 January 2023
SUMMARY NOTES

Minutes of the Board meeting 26 November 2022

There were no amendments and the minutes for the Board meeting held on 26 November were approved.

Strategy update

It was confirmed the working group leaders had met on 4 January ahead of the Board meeting, to agree priorities and actions.

Cost-of-Living update

It was felt as a voice on our own, the Fellowship's was not strong enough and that we should work with other charities. The Huntingdon's Disease Association produced a letter which we co-signed and was sent to the Chancellor of the Exchequer. The letter got a response.

CEO operations

- **Staff appraisals** These have all been booked with staff and once complete, Kirpen will arrange his own appraisal with Gordon and Jerry.
- **Christmas leave** It was agreed in principle the Board will give staff extra days holiday at Christmas, and the decision will be made on an annual basis.
- **Trustees storing data** Each Trustee will be provided with a USB device to store BPF related information so that it is not held on their personal devices.
- **AGM 2023** The Annual General Meeting will be held on 16 September and will be in Yorkshire, if an appropriate venue can be found.
- **Christmas cards** Kripen and the team will select the design and purchase cards for Christmas 2023.
- **Membership** Member numbers have increased compared with last year.
 - The membership renewal page and form will be reviewed and updated.
 - It will be made clear that members need to complete the membership renewal form every year, even if they didn't pay a fee or they pay by Direct Debit.
 - A simple flyer is needed to reach new members and highlight benefits.
- **Partnership work** Kripen and Linda Davis attended a Play Badminton Club fundraising event in December. Kripen will report on how much money was raised at the next Board meeting. Kripen has been invited to speak on 19 March at an event for Sarthak UK, a charity that helps people with disabilities go back to work. His work with Help Cards and Neurological Alliance also continues and is proving to be extremely helpful to the Fellowship.

- **Indoor Games** The same number of members are expected to attend this year, if not more. A committee meeting was held on Monday 16 January to discuss logistics. The Fellowship will also look at the Indoor Games for 2024 and secure a venue. It will be the Fellowship's 85th anniversary next year and the Fellowship needs to decide what anniversary events will take place.

Advisory/Expert Panel Update

The Expert Panel met on 11 January and discussed updating the Covid guidance and information. Carol Levin is leading the panel through updating the factsheets.

European Panel Union Update

Registration is now open for the Polio Conference on 26 May, organised by Polio France.

Healthcare Pathway

A Patient Lived Experience Group workshop was held on 12 January. The workshop went well, and summary notes were being generated. The project manager, Hannah Verghese was doing a good job and a lot of hard work had gone in to getting a good group of clinicians interested. The clinician workshop will be held on 19 January.

Report from the National Treasurer as at 31 October 2022

Terry Blackman commented that overall, the Fellowship was in a strong position, but is running a deficit budget at the moment. This may change as legacies come in. Gordon suggested it was likely the investment portfolio will have risen since Christmas.

Safeguarding and Young Persons at Work policies

Kripen and the Community Engagement and Wellbeing Officer (yet to be recruited) will need to be DBS checked. There were some minor changes to be made to the Safeguarding and Young Persons at Work policy. The revised version will now be employed by the Fellowship and reviewed next January.

Colin Powell and Aidan Linton-Smith

The Board asked that its thanks to Colin and Aidan for all the work they had done on behalf of the Fellowship, was to be minuted. Both Colin and Aidan had given long service to the Fellowship.