

Aspergillus Trust

Charity registration no: 1096281

Minutes of the ordinary meeting held at the Education and Research Centre, Wythenshawe Hospital, Manchester, on Saturday, 7 October, 2006, at 12 noon.

Present: Dr Graham Atherton, Chairman; Jim Breen, Treasurer; June Henriksen, Secretary; Professor David Denning, Peter Henriksen, Jeffrey Hunt, Kate Hunt, Francesca Hunt, Jeannie O'Neill (9)

1. Apologies for absence

Apologies for absence were given by Julia Breen, James Breen, Mike Chapman, Professor Paul Corris, Keith Duxbury, Dr Tom Harrison, Pauline Holland, and John Smout.

2. Minutes of the previous meeting

These were read and adopted by the meeting as an accurate record. They were signed by the Chairman.

3. Matters arising

- **CRP, Rast, IgG, IgE tests:** Jim brought up again the need for these tests to be fully explained in a short article on the AT website so that people understood what they involved and what outcomes they had for patients. **ACTION:** Graham.
- **Epidemiological study:** such a study had been suggested as important in the May meeting, but unfortunately mention of it in the application for Section 64 funding had resulted in failure to secure funding as NHS current criteria forbade funding of research. Notwithstanding this, further attempts to get such a study underway should be taken. Professor Denning suggested that precise objectives and a clear approach should be decided upon. It would be useful to assess where ABPA was being underdiagnosed or there was a span of several years between initial meeting with a consultant and final diagnosis. Dr David Ross had in mind a simple initial study, but there would have to be a clear and useful potential outcome. Any such study would need a lead epidemiologist, a statistician to analyse data, a domain leader, and part-time workers to key in information. Professor Denning suspected that ABPA was to be found in about 1% of all asthmatics in the UK; 10-15% of CF sufferers; all in all about 40,000 people in the UK could have the disease. However, finding out the incidence per thousand of the population is difficult without being able to define clearly the denominator or scope of that population, as some consultants are diagnosing and treating ABPA patients in their area and others are not (hence their 'population' falls out of the equation). This issue would have to be considered carefully before any study was undertaken. Dr Ross to be approached again for an outline plan of the kind of study he envisaged, and how it would be manned/funded. Tom, Paul or David could assess the analysed data. If such a study were successfully undertaken, it could be used by the AT in local advocacy where there

was little diagnosis of ABPA, to encourage chest consultants to review their practice with regard to diagnosis and treatment. **ACTION:** June, all.

- **Involvement of Respiratory Nurse Specialists and Respiratory Physiotherapists:** the former had been mooted by Professor Corris at the last meeting, but no further progress made. It could be greatly beneficial to key into the network of respiratory nurse specialists and to make sure that our leaflets are sent out to all of these for distribution to patients as appropriate. A speaker could be offered for their national meeting. A database of respiratory nurse specialists should be available to facilitate contact. Graham to explore this and to approach Georgina, the Wythenshawe respiratory nurse specialist for her views and support. Similarly, Professor Denning suggested, respiratory physiotherapists could be involved. June to phone Catherine Gow to ask whether Karen Heslop in Newcastle has been approached yet. **ACTION:** Graham, June, others.
- **Conference, Spring 2007:** again such a conference, involving both patients and medical professionals, had been proposed at the previous meeting, with no further progress to date. It was considered that even with the limited budget we would currently have available, it would be possible to organise a venue for a half day/day's Saturday meeting, for example at a Manchester hotel, with Professor Denning speaking on, say, the latest research outcomes/medical update for ABPA/CPA sufferers, with other professionals available for further short talks on say the big issues for patients (ie access to second line drugs if patients can't take Itraconazole; self-management; effectiveness of Voriconazole; genetic factors in ABPA; analysis of the symptoms database information on the FRT website to be presented by Dr Atherton; news about SAFS [Severe Asthma with Fungal Sensitization] research which could affect future treatment of ABPA patients), and group sessions to discuss issues, culminating in a plenary session. Those attending would pay a registration fee of, say, £10, and otherwise expenses would be kept to a minimum. There could be printed leaflets about the meeting, flyers about the website and other websites relevant to sufferers, plus AT medical leaflets available for distribution. Speakers expenses should be paid. Drug companies could be approached for sponsorship, eg Pfizer, Roach, Shering-Plough, Autho-Biotec. Further work on this to be undertaken. **ACTION:** June, others.

4. Treasurer's Report

Thanks were once again very sincerely given to Andrea Breen, consultant accountant, for the help she has given over the year to the Treasurer. Assets at the close of 6 October 2006 stand at: £8353 in the bank; £4460 in the General Fund; £467 in the restricted Leaflet Fund; £213 in the restricted Competition Fund; and £3213 in the restricted Multi-media Fund; a total of £8353. Since the last report, payment of £2500 has been completed from the MM Fund for professional services to Tony Cheetham for the upgrade of the website. This represents outstanding value for the AT with design, programming, maintenance, upgrades, hosting and support all included in the contract. Many thanks to Tony and to John Smout for organising and overseeing such a major upgrade and for his own professional skills in designing the whole site ... well done! As regards leaflets, the 'How can I reduce the risk of Aspergillus infection?' leaflet cost around £2900. We now have two further leaflets in the pipeline for completion and distribution this coming year, on CPA/Aspergilloma and AFS, and should consider the advantages of progressing the leaflets simultaneously and agreeing a joint budget, if this is possible. Jon Cockayne of Baker Tilly Insurance Services is currently seeking quotations for trustees liability insurance for the AT, after Royal & Sun Alliance called for a review of the service they have offered us in the past – it looks as though the premium for this will be raised. Insurance could

now be an even bigger drain on resources and if no satisfactory quotation is received, the Co-op could be approached.

5. Membership Secretary's Report

Julia sent greetings and hoped everyone would understand her absence as she has to care for her seriously ill mother at present. Of the rather disappointing number of only 39 people who had registered with the upgraded website by 20 September, the following data is available: 12 with ABPA, 1 AFS, 1 CPA, 2 IA, 1 relative, 2 doctors, 4 other healthcare professionals. As of 4 October there were 61 registered, so interest is building up slowly. There are about 70 people registered with the old database on the original website, the majority of whom have yet to sign up on the upgraded website. There are 153 registered with ATMG and these must be transferred to the new database. The option for a membership donation has been taken up by only three members so far. There was discussion about what questions should be asked of people registering as members: suggestions included Country, UK postcode, which Aspergillus related disease, which treatments were being followed.

6. Website

It was felt by some, particularly Professor Denning, that the medical leaflets (on ABPA and prevention of infection) should be removed from the members only page and made available to all without registration, as this would encourage more people to use the website and then sign up if they wished to, but not discourage them from downloading these important leaflets. It was felt that this approach might be more valuable for both users and the AT. The Members only page should be made as attractive as possible with the Newsletter, Nutrition and Physiotherapy leaflets, A-Z Tips, news about members' events etc. If possible a map should be placed here with dots showing where members are from and how many there are with each disease from each area. News about conferences and discussion groups/talks/meetings should be given on the website. Dr Atherton said that the time had come for material from the patients' page on the FRT website to be transferred to the AT, and it was generally felt that there should now be only one patients' forum, the Aspergillus Support e-mail group, linked to the AT website. This would mean amalgamating the Aspergillus Support group with the ATMG and the new forum on the upgraded website which had so far had no members, to produce an easily recognizable single forum for all Aspergillus patients from wherever they were in the world. There were concerns that there might be additional liabilities to running this e-mail group and it was felt we should ask Bates, Wells and Braithwaite for their views on the matter. The costs of making the changes to the e-mail groups and website would not be too great, but Tony Cheetham and John Smout would have to be asked whether they would be willing to do a little re-designing. Discussion continued to consider whether the AT should now regard itself as a worldwide organisation rather than just for the UK. Further thought needs to be given to this. **ACTION:** Graham, John, Tony, June.

7. Leaflet

The decision has been taken to try to complete and distribute the next two medical leaflets, on CPA/Aspergilloma and AFS, within this coming year. Dendrite is to be asked again to create an appropriate database for each and send out the leaflets. We need to re-think the list of specialists who should receive each leaflet and agree a budget figure as soon as the range of doctors is known. Professor Denning and Dr Atherton (with Professor Corris and Dr Harrison) are to look at the draft of the CPA/Aspergilloma leaflet as soon as possible with a view to

corrections/additions, so that the text is available to John Smout for design purposes and passing on to the printers. Once this leaflet is well under way, the AFS leaflet is to undergo the same process. Next year the ABPA leaflet will have to be re-considered for currency of content, and some reference made perhaps to genetic risk factors (CF genes being present in some sufferers). Funds must be raised for ABPA leaflet reprinting and printing of the AFS leaflet. The third meeting of the Approaches Against Aspergillus group is to take place in January 2008 when they hold a conference in Florida. They have considered the possibility of a pre-meeting with patients, as some patients already approach doctors at this conference. As the only Aspergillus charity in existence, to our knowledge, the leaflets of the Aspergillus Trust should certainly be made available to members at the conference, and by then we should have four leaflets off the press. Professor Denning could take a batch across with him. **ACTION:** David, Graham, Tom, Paul, June, John, Peter

8. Competition for medical students

The wording of the next competition was considered by Professor Denning and alterations made. The text is now ready for John Smout to create a design for the poster and forward it to the printers. The letters and posters are to be sent out by June and Peter as soon as possible. There is to be mention of a second prize of £100 on the poster. **ACTION:** June, Peter, John.

9. Fundraising

After putting a lot of effort into his first application for Section 64 funding and feeling distressed by its failure owing to lack of clarity of definition of NHS criteria, Peter is still going to try again in the spring with a further application. We need to study the successful applications of other bodies, available on the internet. Several other approaches to organisations have failed to come to anything in the past year. But nevertheless continued attempts will have to be made in order to put our activities on a secure footing. Jim suggested we approach Awards for All in our own localities for funding for local distribution of leaflets. He intended to try such an application, and had been encouraged in this by EAVS, the Eastbourne volunteer group. Graham mentioned the advice he had received at the recent Charity Fair he attended on behalf of the AT to concentrate on getting local support in our individual districts, and not to go for national funding yet, as it probably would not be available to us. A further approach to Lloyds TSB may be fruitful, as they have already supported our website upgrade. We need to let them know how well it is doing. We must also make applications to companies who supply items needed by Aspergillus sufferers, such as allergy products companies, 3M who supply spore resistant masks, B&Q who supply products using HEPA filters, companies such as Dyson who manufacture vacuum cleaners with HEPA filters. There was a discussion about the AT objectives rewritten by the Charity Commission in two short paragraphs which seemed to overemphasise the desire to raise funding for research which is clearly a distant hope. Peter and Jim thought the reference to this should be omitted to help us in our funding applications. June thought that most charities would have funding for research as an objective and that the NHS had made it clear this was not the reason for refusing the bid for funding. However the wording could be reconsidered perhaps in future, if further problems arose. **ACTION:** Peter, Jim, Graham, all.

10. Planning for the future

This had largely been covered in other topics.

11. AOB

- **Translations of leaflets:** Graham said he had made the acquaintance recently at work of a number of people with medical backgrounds who might be willing to translate one or more of our leaflets into their native languages for our website: Greek, Spanish and Polish were the languages mentioned. **ACTION:** Graham.
- **Database purchase and use:** It would be very useful to have a database available ourselves of chest consultants who diagnose and treat ABPA and other Aspergillus diseases in their patients; if the chest consultant database could be bought from Dendrite, then a letter could be sent to each consultant asking them to let us know their position re Aspergillus diseases. **ACTION:** Peter, Graham, June.

12. Date, time and venue of the next meeting

These are to be decided, but the next meeting should be about Easter time.

The meeting closed at 3.15 pm.