**FORWARD-ME**

**MINUTES OF THE ZOOM MEETING HELD ON**

**FRIDAY 10 JULY 2020 at 2.00 pm**

**PRESENT:** Countess of Mar Chairman

Carol Monaghan Deputy Chairman

 Catherine Frazer Assistant to Carol Monaghan

 Suzie Henson-Amphlett Tymes Trust

 Tony Crouch Tymes Trust

 Debbie Burgess Tymes Trust

 Sue Waddle ME Research UK

 Jonathan Davies ME Research UK

 Dr Louise Crozier ME Research UK

 Helen Winning ME Trust

 Dr Charles Shepherd ME Association

 Russell Fleming ME Association

 Laurie Jones #ME Action

 Denise Spreag #ME Action UK

 Natalie Hilliard PhysiosforME

 Nicola Clague-Baker PhysiosforME

 Janice and Bill Kent ReMEmber

 Sonya Chowdhury Action for ME

 Sam Bromiley Action for ME

 Christine Harrison BRAME

 Nina Muirhead

 Dr William Weir

**APOLOGIES:** Dr Nigel Speight

1. The Chairman introduced Sonya Chowdhury who, as well as being CEO of Action for ME had, with her team, been the driving force behind the success of the funding application for the DecodeME study.

Funding of £3.2 million was announced on 23 June 2020. This was the culmination of more than 8 years of hard work.

The CMRC had been advocating and lobbying funders for some time for biomedical research. She explained that, despite the criticism of the CMRC for not doing much, they had in fact held numerous meetings with potential researchers and funders. At the end of last year, they were invited to submit an application that was not open to competition with any other research groups or illnesses. Though the CMRC they pulled together the Biomed Partnership between the University of Edinburgh led by Chris Ponting and the London School of Hygiene and Tropical Medicine led by Luis Nacal and Elyana Lacerda and, most importantly, people from the ME community. This included people with the illness as well as carers. They set up a management group. They worked together with others to submit an application to the MRC in January 2020. Although they knew earlier, they had to wait until they were in a position announce the success of the application.

The study is the genome wide association search for the biological causes of ME. It will be undertaken through the recruitment of 20,000 people who would need to complete a detailed online questionnaire which had been tried and tested and was validated. The management group were trying to make it as accessible as possible. People who were recruited to participate in the study had to meet very strict research criteria. There was a workshop funded by the MRC with wide international participation last year at which it was agreed that the CCC and IOM criteria would be used, with post exertional malaise being mandatory. There was then an online survey to obtain people’s views more widely.

If people meet the research criteria, they must have a diagnosis of ME, they must be based in the UK and they have to be over the age of 16. If they meet the criteria they would be sent a saliva spit kit to be used as directed and returned by post to the NIHR Milton Keynes Bioresearch Centre where the samples would be processed and the data sent to Edinburgh where Chris Ponting and the team would undertake the genetic analysis. They will analyse the genetic data from the saliva, looking at around a million common variants in the DNA and will compare them with healthy controls taken from the UK Biobank – not the ME Biobank. It is an ambitious project in terms of getting 20,000 people who meet the specific criteria and return their spit kits, which are quite expensive. They will need to recruit 45,000 people in order to achieve the target.

There was a Christmas campaign through a temporary website which invited people to show support for the application. Their data was retained. Since the launch on 25 June when people were asked to sign up through the new website (DecodeME.org.uk) over 23,000 people had signed up. More than 16,000 said that they were over 16, lived in the UK, had a diagnosis of ME and were willing to participate. Whilst this was very reassuring, there was still a long way to go. The input and support of the Forward-ME charities to promote the study as much as possible would be very welcome. Funding begins in September, though the Action for ME team have been working on the project for several months without funding. Provided ethical approval is received, recruitment was expected to begin early in March 2021, but this was not yet a firm date. One of the key parts of the study was patient public involvement (PPI) steering group which both the ME Association, as a founding member of CMRC, and Forward-ME and representatives from the Patient advisory group of the CMRC and Science4ME. The possibility of extending the group was being considered. It was important that PPI was embedded in every aspect of the project. Both the MRC and the NIHR regarded this as being critical and was one of the key reasons for funding. They regarded this as the first time for a community come together for what they expect to be the first of more research – called a ‘door opener’ by the funders. It was important that PPI was done as well as possible. The CMRC would be looking at possible future research in order to ensure that there would be projects to continue with funding.

Sonya then paused to respond to questions. Christine asked whether people wanting to get involved should do it through the Action for ME website. People were being encouraged to do it through the DecodeME.org.uk website where there is a Frequently Asked Questions section. Those who could not deal with the internet and had no family or carers who could do it for them the ME Association and Action for ME would use their resources to assist. Ideally, people should sign up online, but those who could not would be supported. There was a Webinar held earlier in the week when nearly 2000 people registered. The webinar was available online for people to watch and work on bitesize chunks.

Christine asked whether the study would look at cases from acute/early stage ME to the long-term severely affected to see whether the genome had changed. The study would be across the spectrum and details of people who thought they had ME but did not meet the criteria would, with their consent, be retained for other researchers to use. Genetic data would be linked to health data for analysis.

Denise asked whether people who had recovered or were in remission, especially young adults, would be included. Because ‘recovery’ and ‘remission’ were used in several different ways people were being asked to complete the online questionnaire and the team would work out the eligibility. Denise from #ME Action would be happy to amplify the message. Sonya said that in September they would be working on their recruitment strategy – reaching out to groups, thinking about posters in GP’s surgeries.

Suzie Henson-Amphlett asked whether there would be anything in the research that would connect extended families as well as immediate family members where there were multiple cases of ME. This would be a later stage in research.

Willy asked whether the researchers would be looking at the mitochondrial genome as well as the nuclear genome. He explained that the mitochondrial genome was likely to be where abnormalities and dysfunction would be found. Sonya would check with Chris Ponting and circulate the response.

 [The UK Biobank does test for sequence differences in the mitochondrial genome. Also, and this is not obvious, most DNA mutations that affect mitochondrial function do not occur in the mitochondrial genome, but instead in the nuclear genome. This is because the mitochondrial genome is much diminished, containing only 13 protein coded genes, whereas at least 1,100 nuclear genes produce proteins that act on the mitochondrion. (Sonya 13 July)]

Debbie asked how the fact that many people could not get a firm diagnosis of ME would be affected. If they had a ‘probable’ diagnosis they would be encouraged to sign up. The questionnaire was designed to ensure that even without a firm diagnosis those who met the specific criteria would be included.

Sonya then went on the describe the James Lind Alliance Priority Setting Partnership (PSP). It was funded by the NIHR. It had been offered, through Professor Chris Whitty, some 2 ½ years ago, but it was felt that acceptance at that time might prejudice funding for the genome study. It was an approach used through the James Lind Alliance who have a tried and tested methodology for working with people with an illness, carers and clinicians to develop the top ten research priorities that can then be used strategically to secure funding. More than 100 PSP had taken place over a range of different illnesses, some with greater success than others. For example, the multiple sclerosis PSP had led to £multi-million funding. A seed steering group which included Russell Fleming as representative of Forward-ME. They were looking to recruit people with ME, parent and clinicians to a steering group that would oversee the priority setting partnership. They would set up an open and wide consultation which would ask people about symptoms and what they think are research priorities. An information specialist would compile the responses with what we currently know from research and evidence. They would develop a shortlist of questions. A second consultation with the ME community. Those responses would be distilled down to a top ten list to be used with the mainstream funders to influence funding for the future. Communication with the MS Society showed that research that had been undertaken bore no resemblance to their top ten. They have been able to transform their research programmes through the PSP and money was flowing in. It is hoped that the PSP will be able to strategically influence future research funding. It was clear that the NIHR would not be funding the PSP if they did not believe that the outcome would be beneficial. They were currently in the process of recruiting people who would come together to oversee and steer the PSP so that in 12 – 15 months’ time they would be able to work with the funders to define the next stage. Details for participation could be found on the PSP website (psp-me.co.uk).

The Chairman thanked Sonya for her clear explanations of both Decode-ME and the PSP. She also expressed thanks for all the hard work that she, Clare, Sam and James from Action for ME had done over recent months to put this work on its feet.

1. EDUCATION

The Chairman asked Nina Muirhead to say what had been happening with her work on medical education of doctors. She had had a good start to the year with the education group of the CMRC. There had been training sessions for GPs in Buckinghamshire, Solihull and Birmingham and Higher Education Improvement Wales. It was an excellent way of determining what GPs want to know as well as for finding ways of targeted ideas around face to face learning. Based on that and on information from pre and post testing questionnaires, with the help of others, she developed a 10 face-based learning module which was put online on 11 May for ME Awareness week. In 2 months there had already been more that 1,000 downloads. 97% doing the online module would recommend it. Before doing the module, healthcare professionals agreed that biomedical research was important in 87% of cases. When they finished the module, that was true in 98% of cases. 98% agreed that more formal education on ME/CFS was required. The results also showed that many healthcare professionals did not understand what ME was really like. They were picking up a lot of gaps in knowledge and misconceptions. Russell Fleming had a list of nearly 800 GPs who would be invited to take part in the online learning in the hope that more online data could be collected. It was a start in finding the direction for education, particularly when the new NICE guideline would be published. There was a new group – NursesforME, who had their inaugural meeting on 22 June 2020. There may be an opportunity for nurse practitioners who are familiar with ME and doctors who to support the recruitment. Also, confirmation of diagnostic criteria for patients unable to obtain a diagnosis possibly could be arranged.

Charles Shepherd said that he had been having a discussion with Dr Gregor Purdie, a GP based in Scotland, on the possibility of having GPsforME. He seemed keen to take this on. Every GP on the ME Association list was to get a copy of the new MEA Purple Book which was to come out the following week. It would cost the charity £7,000 which they thought was worthwhile. He asked anyone who knew of GPs who might be interested in joining GPsforME or who might like a copy of the Purple Book to let him know.

Debbie Burgess asked whether there as any way in which this could be pushed towards paediatricians as it would be really beneficial. There followed a discussion about inviting Dr Ben Marsh whether he would be interested in recruiting paediatricians with an interest in ME in children. He was known to both Nina and Charles who thought that he would be very helpful. The Chairman agreed to write to him with the proposal.

Christine Harrison asked whether the training module could be accessed online. Nina would provide a link.

Denise Spregg said that #ME Action had an education project which had to be suspended because of COVID-19. She would contact Nina to see whether they could re-purpose it. She said that Nina’s work was outstanding. This was generally agreed.

1. The minutes of the meeting held on 10 July 2019 were agreed.
2. **MATTERS ARISING.**
	1. Medical Education – see above.
	2. NICE Guideline Development Group.

Charles Shepherd reported that work on the guideline was suspended on 6 April 2020 because of COVID-19. The full committee had not met since. Both the Chair and Vice-Chair of the committee were keen to get moving and the next full committee meeting would be on Monday 13 July. There would then be a series of weekly meetings from then into August to try to get back on track. It was very unlikely that the target for publication in December 2020 would be met because of the pandemic. The current aim is to publish in the Spring of 2021. There were two sub-groups. Charles is on the Severe sub-group and Tony Crouch is on the Safeguarding sub-group. Both had been working during lockdown. They were going into these areas in some depth as it was appreciated that the importance of both had been underestimated in the previous guideline. NICE had set up focus groups because children and adolescents and people with severe ME were not getting attention.

Charles pointed out that President Trump’s advisor, Dr Anthony Fauci, on COVID-19 who is also senior in the US National Institute for Health made a statement which backed up what most people in the UK were saying. There was a major issue for people with Post COVID symptoms. He was quoted as saying: “there are chat groups that you just click on and see people who recovered that really do not get back to normal. They report symptoms such as brain fog, difficulty concentrating and fatigue that resemble the symptoms of ME”. Laurie Jones said the #ME Action in the USA were thrilled that Dr Fauci had made that statement and would be following up immediately. They will be reaching out to many working in this field in the UK and would be arranging a UK seminar.

There was a discussion related to concerns that post-COVID19 patients would be persuaded to follow graded exercise regimes. Several people, many of whom were on the NICE GDG, wrote to the Chair and Vice-chair of the committee asking that the good advice given by the ME Association relating to pacing be passed to those responsible for rehabilitation of post COVID19 patients. It appeared that the current online rehabilitation was emanating from Leicester. PhysiosforME were in contact with the main physiotherapist there. There were several researchers also based on Leicester. Charles suggested that it would be helpful if there could be a link between them and the ME charities.

[ Statement from NICE: “NICE is aware of concerns about graded exercise therapy (GET) for people who are recovering from COVID-19. NICE’s guideline on ME/CFS 9CG53) was published in 2007, many years before the current pandemic and it should not be assumed that the recommendations apply to people with fatigue following COVID-19. The recommendations on graded exercise therapy in CG53 apply to people with a diagnosis of ME/CFS as part of specialist care, and CG53 is clear that this should be part of an individualised, person centred programme of care, with GET only recommended for people with mild to moderate symptoms.

As the guideline is currently being updated, it is possible that these recommendations may change. The evidence for and against graded exercise therapy is one of the important issues the guideline committee is considering. NICE plans to consult on the updated guidance in November 2020.”]

4.3 Whitehouse Publications.

 Philip Gowan had several meetings with Whitehouse Publications. They liked our proposal but, on this occasion, they could not provide their services.

4.4 DWP

 The Deputy Chairman reported there had been no major moves

 since the meeting with the Minister in June 2019. There did not

 seem to be many problems reported by MP’s constituents. These

 were usually a good measure of the situation. It seemed that the

 DWP were aware that MPs were watching not just ME cases but

 also, others with medically unexplained symptoms and non-visible

 disabilities.

 Carol reported that the All-Party Parliamentary Group for ME had

 been set up because there were many MPs who had contacted

 her asking for an APPG. The first meeting was in January 2020.

 were about 100 MPs who had expressed an interest which was

 incredible. They had a clear programme of inquiry. The first one

 in March 2020 was with Professor Chris Ponting, Dr Eliana Lacerda

 and Professor Julia Newton. The discussion was on biomedical

 research. The meeting on 16 June focussed on the issues with

 children and families. Dr Nigel Speight, Tony Crouch and the parents

 of a child with ME. She was finalising letters to be sent to the Chief

 Social Worker for Children and Families and to different Health

 Trusts raising issues around families being able to have an

 advocate and other matters that were raised at that meeting.

 Carol then spoke about Post-COVID fatigue. She felt that the use of

 the word ‘fatigue’ gave a false impression and she no longer refers

 to CFS when talking about ME. The Chairman mentioned that in the

 PPI there had been a discussion about the need for a word other

 than ‘fatigue’. She asked the group to think about a word that

 would signify the severity of the symptom. Christine Harrison gave a

 graphic description of the awfulness, but the Chairman asked for

 just one word. The APPG had written to the Oxford NHS Trust to ask

 them to remove graded exercise from their post-COVID advice. The

 next APPG meeting was likely to be specifically on DWP.

 Christine asked whether Carol had any contact with Atos/IAS,

 because Capita were continuing with Zoom meetings but Atos/IAS

 were not. She had not. Christine would follow up. Charles said that

 Zoom meetings with Maximus which were also being attended by

 DWP officials. The next meeting was scheduled for 8 August 2020.

 He said that there was very little activity in the form of complaints

 as a result of lockdown. He offered to take any general problems

 that had occurred over the past 3 months to the meeting, though

 he couldn’t deal with individual cases. Christine said she had heard

 that more paper-based reviews had taken place during lockdown

 and asked whether anyone had any feedback on cases.

 Carol agreed to probe on paper-based decisions. She

 that any ME related problems with DWP should be sent to her

 office. [N.B. Paper-based and telephone assessments had been

 taking place during lockdown and the DWP were in the process of

 restoring normal practice – Times 15.07.20]

 Debbie Burgess asked whether conversations with the

 DWP had included benefits for children. It had been mainly

 focussed on adults but the issue was raised at the last APPG

 meeting. PIP cases had a better outcome than the work related

 benefits which did not affect children. Carol would have a separate

 Carol would have a separate discussion with Debbie.

 Russell asked whether anyone had any information about Social

 Care being arbitrarily cut by local authorities with no assessment

 or review. The ME Association had received a steady stream of

 concerns. Sam reported that Action for ME had raised similar

 concerns with Luke Hall, Minister for Local Government when

 they saw the changes being introduced with local authorities

 disregarding their Duty of Care. Action for ME advocates had

 been trying to help people express their views to their local

 councils. Carol had not encountered the problem as the system

 was different in Scotland. She would follow up with colleagues.

 Debbie Burgess mentioned that Tymes Trust was beginning to

 hear about cuts in children’s Health and Social Care Plans. Tony

 Crouch believed that it was illegal to cut a person’s budget without

 reassessment.

4.5. RCGP Conference

 Sam Bromiley that Forward-ME representation at the Conference

 had been a success. Things had changed radically since then and

 much thought would have to be given. Having representatives from

 the different charities had worked really well. Action for ME had

 made some useful contacts for GPs who had been sent Nina’s

 module. This year’s conference had been postponed. Attendance at

 future conferences was not something that they could commit to.

 This applied to all the Forward-ME charities. The situation would be

 kept under review.

 Charles said that attendance at future conferences should certainly

 be considered, though he appreciated that Februry2021 would be

 too soon. All his interactions with GPs were positive. The ME

 had also picked up many GP contacts and with Nina thy had received

 an invitation to speak at the Cambridge Medical School. This had to

 be postponed because of COVID19.

 Sam said that they might have had a presence had the publication of

 the NICE guideline not been delayed again.

4.6. Research

 Louise Crozier, who is Science and Engagement Director for

 MERUK, gave a brief review of the projects that MERUK had funded

 an update on applications in progress. She had a short lay

 summary of each of the projects which she would be happy to

 circulate. Three publications had resulted from MERUK projects

 this year. The first was from Berlin where work was being done on

 the immune system. Previously they had found that 1/3 of ME

 patients had increased levels of autoantibodies directed against

 antigenic receptors. In the latest study they found that the

 antigenic receptors in ME patients were not responding as well as

 they should. There is a sub-group who are a potential area for

 targeting for a treatment. Julia Newton’s laboratory were looking

 at the metabolism of bed-bound and housebound patients. In both

 groups, mitochondrial function was reduced to a similar extent.

 This suggested that it was not a result of deconditioning so there

 must be a biological reason for ME. They also suggested that there

 was a fault in the metabolic pathways that was more obvious in the

 severely affected. A paper from Belgium looking at painful stimuli

 in situations of danger. They discovered that there was no

 difference between ME patients and two different groups of

 controls.

 There were two more projects that MERUK had recently funded to

 The extent of £100,000. One will be a follow-up to the Belgium

 looking at potential factors in membrane. There are 9 applications

 that are looking for grant or PHE funding. The total request is £1.1

 million, but not all the applications will be successful.

 Jonathan Davies pointed out that the comments that Sonya made

 about the PSP were particularly relevant because MERUK was

 providing funding for proof of concept in many cases. This would

 work well with the PSP objectives. The opportunity to really focus

 on what was needed rather than what researchers think they want

 is potentially quite powerful.

 Charles reported that the ME Association had just awarded a grant

 to PhysiosforME and colleagues in Leicester to do the first UK

 study of the cardiopulmonary effects of exercise – basically the

 Workwell test which possibly has some ground as a clinical

 assessment test. Natalie had contacted Leicester to try to find out

 in detail what they were doing with post-COVID patients. She felt

 it was important that they linked up with the research work that

 was being done with ME patients. She had also contacted

 Professor Rob Copeland at the National Sports Centre in Sheffield

 where they were also doing post-COVID work. He was unfamiliar

 with the exercise physiology work at Workwell. He has a number of

 exercise physiologists working with him. They are keen to that she

 keep in contact with them as they are keen to explore the exercise

 physiology concept with post-COVID patients. There is the potential

 to investigate the links between them and ME patients and to try to

 find the point at which post viral fatigue to post viral fatigue

 syndrome.

1. POST COVID19 CONCERNS

The Chairman mentioned the Freedom of Information request she had sent to NHS Digital about the online recovery programme for post-COVID19 and had forwarded to the group. She would advise when she had the response.

Natalie Hilliard was pleased that the FOI questions had been asked. They had been receiving emails about the NHS post-COVID leaflets and the recovery programme. Dr Weir had mentioned the reconditioning approach spoken about at Headley Court rehabilitation centre. Most post-COVID patients would respond to that, but there were 10 – 15% of patients who would not respond. That message was being left out of leaflets. She asked whether there should be some kind of combined approach should be taken as, during the COVID crisis, they had written numerous letters and emails to different organisations producing guidelines. Was some kind of standard response needed? She was looking for advice as to how to manage it. She felt that they were fighting fire all the time with the number of publications being put out.

The rehab approach needed to be modified as it was likely that some patients would not recover.

Sue Waddle commented on the number of quangos in the NHS who were failing to coordinate activities. She said that the first letter to the Oxford NHS Trust produced by the Group was comprehensive. It was a question of being quick off the mark. As soon as a defective leaflet was found the letter should immediately be sent to the authors with minor adjustments such as changes to headers and footers. This could go out with their leaflet. Nicole said that they did not have a leaflet, but they could send the very comprehensive information that the ME Association had produced. Dr Weir pointed out that the 2007 NICE guideline for ME was still extant. He and Charles had tried to persuade NICE to withdraw the GET advice, but they had not heard back. He kept hearing that people were still quoting the old guideline. Louise Crozier said that #ME Action was working on a campaign to persuade people to email Matthew Hancock, the Secretary of State for Health, about the post-COVID recommendations. The Deputy Chairman suggested that she could table an Early Day Motion on the subject. She would consult with her colleagues.

Suzie Henson-Amphlett mentioned that there were a number of medical people who had what they call ‘long-term COVID communicating via social media. She understood that many medical people tended to connect and share information via Twitter as it is a simple and responsive platform. She wondered whether Group members who were on social media could join in ‘conversations’ and direct people to suitable links. Charles was already communicating with a number of medical professionals in this way. There was a big professional network who tended to listen to their own and would likely pass on useful information. The information had to be good quality and correct. The ME Association post-COVID information was high quality and freely available on the MEA website. Sue Pemberton, Occupational Therapist at Leeds, had produced a very good leaflet for OTs, as was the material from PhysiosforME.

It was agreed by the Group that Natalie should send out the original letter, suitable adapted, as Sue Waddle had suggested. There were no dissenters. Russell Fleming offered to help Natalie if she was overburdened.

Christine felt that communications were extremely helpful to post-COVID patients.

Sue Waddle was concerned that communications should not include ‘fatigue’ and that the illness should simply be referred to as Post COVID syndrome. This was also agreed. Russell pointed out the Post Viral Fatigue Syndrome was recognised by the WHO and was a medical term, so it might be difficult to get rid of. Sue thought that if we didn’t use it it would soon fall out of use.

#ME Action had just started a Facebook page called LongCOVID specifically for giving advice to post-COVID patients. They could create a page specifically for medical professionals posting information such as that from the ME Association. Suzie understood that medical people tended to share their information via Twitter as they did not have to log in. That should be borne in mind.

1. CHILD PROTECTION

Tony Crouch wanted to follow up what Carol had already said. He wanted to know from Charles what was planned after the APPG meeting such as who was going to be written to; and from Sam specifically how far they had got to with the letter to Isabelle Trowler, the Chief Social Worker for Children and Families trying to get her to sign off a leaflet for social workers that was worked on last year. Something really needed to be done as the cases were continuing. There need to be balance as some local authorities were including in their child protection procedures presentations which were widening the whole scope of Fabricated or Induced Illness definitions to include unexplained symptoms. They went much further than the original term of Munchausen by Proxy. There is an increase in the number of families being dragged into the net. Following the excellent article by Sean O’Neil on the subject in the Times, Tony asked how we could take it further. Sam would ask his colleague and would let Tony know. He asked whether anyone had contact with Sir Andrew McFarland who is the President of the Family Division. As a barrister, he presented a judicial review case for a family with a child with ME defending the opinions of Dr Franklin and Dr Speight which had been rejected by a local authority in preference for other opinions which had a successful outcome. It was possible that, in his current position, he could exert some influence. Sue suggested that his email address might appear on a website and he could be written to directly.

Charles said that he could not say any more than had already been said by Carol. He suggested that Tony write to Catherine – Carol’s assistant, to ask what the current situation was. Tony said that he had recently discovered a recent online forum of the British Association of Social Workers where there was a very good presentation on epilepsy which was suffering much as ME. He would follow that up and see whether he could get them to focus on ME.

1. FORWARD-ME WEBSITE.

The Chairman expressed her sadness that Alan Rengger, the website manager, had died. Unfortunately, his final illness happened too quickly to enable a proper handover. She asked Charles for assistance. It was agreed that Tony Britten from the ME Association would liaise with Alan’s son to transfer the site. They had managed to get into the website and to copy it so it is safe, but they cannot alter anything because they cannot break into the content management system. Alan was the only person with the tools to do it. It needed someone who was able to break into the system so that it could be managed. Janice Kent knew someone who might be able to solve the problem. Janice had put the person in touch with Tony and will be sorted out.

The Chairman asked Charles to thank Tony and to advise her as soon as the site was functional.

1. PRIORITY SETTING PARTNERSHIP

Russell Fleming had sent a report to all of the Group. They had to have a chairperson who would not interfere with the ME aspects. She was independent. They were looking at applications for 8 positions on the Steering Group from a wide range of people with or associated with ME. They had to allocate three people to each category – for example 3 clinicians: 3 patients etc. When the membership of the Steering Committee is settled, they can start work on public consultations. It sounded a very simple process to come up with 10 basic unanswered questions about research for people with ME. Going through the process will take time – possibly 18 months.

Sam is the PSP coordinator responsible for the administration.

1. ANY OTHER BUSINESS

Charles suggested that the Chairman contact Sean O’Neill senior reporter for the Times to ask him to address the Group on the media. This was agreed.

It was agreed that the Group would meet again in September.