



Promoting effective joint working by ME and CFS organisations to maximise impact on behalf of all people with ME and CFS in the UK

Forward-ME Minutes of the Zoom meeting held on Wednesday 9th September 2020

Present:

Margaret Mar, Chairman
Sam Bromiley, Action for ME
Simon Chandler
Tony Crouch, 25% ME Group
Christine Harrison, BRAME
Sue Waddle, ME Research UK
Jonathan Davies, ME Research UK
Louise Crozier, ME Research UK
Nigel Speight, ME Association, 25% ME Group

Nina Muirhead, CMRC Medical Education Group
Suzie Henson Amphlett, TYMES Trust
Charles Shepherd, ME Association
Russell Fleming, ME Association
Laurie Jones, #MEAction
Bill and Janice Kent, ReMEmer
William Weir
Helen Winning, ME Trust
Catherine Frazier, Office of Carol Monaghan, MP

Apologies:

Carol Monaghan (Vice-Chair), Debbie Burgess (Tymes Trust), and Physios4ME.

1. The Chairman welcomed Simon Chandler as a new member to the Group. His experience as both a patient with ME and in the NHS would be beneficial.

2. Sean O'Neill, Chief Reporter to the Times was also welcomed. He explained that he was going to talk about the media in general, how he thought it worked and the best way to use it.

- People tend to make the mistake of seeing the media as one monolithic organisation. The reality was that, although it had many common features, it is driven and riven by competition. Everybody wanted their own story, seeking something new, unusual, shocking, powerful human story or preferably a scandal!

- Entry into the media was not just about transmitting a message that was important, expecting it to be picked up and responded to. It very rarely worked. Engagement with the journalist with an interest in the subject was essential. Contacts and personal initiative and connections in order to find the right person to take on the story were necessary.

- The right timing was also important. Timing could be upset by events, such as a major disaster which would prevent other news items from being reported. He suggested that there should be a plan but there should also be a plans B and C.

Sam Bromiley asked what the best way was to maintain momentum in an unchanging landscape. Sean felt that DecodeME was a massive breakthrough. As that story unfolded there would be a series of milestone hits which would need to be focussed on with a media strategy with targets such as the BBC, Sky, ITV as well as the Press. Tell the same story, but tell it in a different place.

Sue Waddle was concerned that the Science Media Centre appeared to pre-empt stories that were about to be published. She wanted to know how much influence the SMC had on what was published. Sean said that he did not really know. He was not a science or medical journalist. He approached ME with a strong personal interest. He had never had any dealings with SMC. He recommended ignoring them rather than entering combat. He felt that SMC influence was diminishing. It was better to concentrate on credible media outlets, making the message as strong and as human as possible.



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Charles Shepherd remarked that, as a non-health journalist, Sean had done more for ME than anyone else recently. He asked whether press releases normally sent to health reporters should also be directed to people like him. Sean advised reaching out to interested reporters in the media. When he started to write about ME he found that there were a lot of journalists with personal experience of ME who would not be influenced by the SMC and its narrative. These were the people who needed to be reached out to. The right way would be to develop a narrative from the patients' perspective.

Nigel Speight thanked Sean for the help that he had given on a case. He expressed his increasing concern about the Royal College of Paediatrics and Child Health (RCPCH) the higher echelons of which appeared to be deeply embedded in the fabricated and induced illness (FI) story. Even when paediatricians had not diagnosed ME somehow the FI machinery had been activated. He was concerned that it was getting worse. He referred to a conference on medically unexplained symptoms supported by the RCPCH. He felt there was a potential story based on some paediatricians' predilection for suspecting every family where they were slightly perplexed of FI. This needed to be rebutted. Sean thought that there needed to be some investigative work. He had made some preliminary enquiries and had had difficulty in obtaining reliable statistics to back up the arguments. He was interested in the study day conference. Nigel would send details. Nigel was aware of one paediatrician who had 130 families under surveillance for suspicion of FI. Sean asked whether FI applied to other conditions apart from ME. Autism and food allergies were also a problem, but ME was the most serious.

Catherine Frazier intervened to say that Carol Monaghan was to have a meeting with Professor Russell Viner, current President of the RCPCH, as one of the MPs in the APPG had a connection with him. She would need input from Nigel prior to the meeting. Carol had been writing to key people about the problems with children with ME. She would update us at the next meeting.

Willy Weir, in support of what Nigel had said, added that a real iniquity apart from FI was that some patients were still being subjected to graded exercise. He could produce a number of clear-cut stories where teenagers with ME whose illness had deteriorated progressively were admitted to hospital able to walk were forced into a programme of graded exercise who left the hospital in a wheelchair and, in some cases had to be tube fed as they were no longer able to chew and swallow their food. The case histories were absolutely factual and could be worth publicising. Sean explained that the difficulty was to find an angle that was newsworthy. If a story on FI was forthcoming it would provide an opportunity to air those histories.

Suzie Henson-Amphlett thanked Sean for his articles in the Times. Debbie Burgess of the Tymes Trust always had live cases where there was social services involvement. They had produced a survey in April 2020 which had highlighted several concerns. Figures had been updated. She thought that Debbie would appreciate an opportunity to talk with Sean. Sean explained that it was difficult for him to go to his news desk to say that he had an update on a previous story. Perhaps they should find another outlet so that other journalists could spread the message. Suzie said that there was quite a lot going on at the Trust with COVID19 and its effects on children and schooling and they would be happy to provide information when wanted.

Janice Kent said she had a psychotherapist friend who had three sick children who had been misdiagnosed. She was sure that she would be happy to publicise their story. Sean had noted it and would go back to Janice if he needed to.



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Laurie Jones asked about disseminating stories through local news outlets. She asked whether Sean had a strategy for using local press to build a story that might be taken up by the national press. Sean repeated that it was about making connections with journalists. Unfortunately, local newspapers were dying. Local support groups and local networks should find local journalists who would be eager to take on new stories. He recommended an organisation called Bureau Local. It had done a great deal on homelessness, working with local journalists to coordinate and tell stories of people living rough all over the country. It could do something similar for projecting ME stories. They could bring together local journalists under a national umbrella.

Christine Harrison thanked Sean for putting his head above the parapet. She had done a lot of work with local press and radio. She agreed with Sean that the local press was not as effective as it had been, but local radio was always helpful. He agreed that local radio was particularly strong. They had time and it was possible to tell stories. He suggested that the connection between ME and long-COVID should be emphasised. More and more people were aware of the effects of isolation in their homes. The ME experience would chime a lot more with people than it did before the pandemic.

Simon Chandler thought about objectives – to raise awareness and to prevent wrong treatments being given to people. He gave an example of a professor of medicine who had COVID19 being diagnosed by a proponent of the psychosocial model of ME as having anxiety without being examined in person and with no evidence. How could a clinician diagnose without seeing patients? There was a YouTube video showing this. Sean asked for the link to the video. It was called Spotlight on Covid. As Sean was unable to deal immediately, he would get someone else to deal with it.

Sean described the huge impact that the pieces on DecodeME had online. There was a lot of incredibly positive feedback. Emphasis should be on the positive steps around DecodeME and, he hoped, on the new NICE Guideline, as well as the international progress that was being made. This was better than expending energy in engaging with the psychiatric lobby which was becoming redundant.

Nina Muirhead told the Group that doctors had lots of sayings, one of which was: "If you hear the sound of hooves think horses, not Zebras. ME is the horse and weird psychological explanations are zebras. She suggested that doctors were not being trained to recognise the sound of hooves.

Margaret Mar thanked Sean for giving up his time to meet us. She wished him a speedy recovery and asked that lines of communication be kept open without overburdening him. He had been more than helpful to the Group.

3. MINUTES OF THE MEETING HELD ON 10 JULY 2020

The minutes of the meeting were agreed.

4. MATTERS ARISING

Medical Education:

4.1 Nina Muirhead told the Group that the CPD online education module had been going very well. There had also been an invitation from the BMJ to pitch an education piece on ME, and an invitation to write a 6-week master class on ME. There was also some potential interest for an opinion piece on 'Is ME the same as Long COVID' for the BMJ. The Cambridge teaching event that she, Charles and Caroline from the ME Association were hoping to do in the summer would move to October.



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4.2 Margaret Mar had corresponded with Dr Ben Marsh with a view to him forming a Paediatricians for ME group. He explained that he was not well enough to do it.

5. FUNDING FOR FORWARD-ME WEBSITE

Charles Shepherd explained that no progress had been made in getting into the current website because Tony Britten had not the necessary tools to access the site. There were three options. He had a telephone conversation with Ruth at AfME who has someone at AfME who was willing to attempt to gain access. Failing that, meeting minutes could continue to be put out by each of the members of Forward-ME, which was not satisfactory, or a completely new website could be developed.

Charles had spoken with Caroline Cavey at the ME Association. She produced websites and was willing to develop one for the Forward-ME Group. She had given an estimate of £900 - £1,000. Other estimates would be obtained. The major charities had agreed to jointly fund the new website. MERUK and ReMEmer would also contribute. Margaret hoped that some conclusion would be reached before the next meeting.

Laurie Jones said that #MEActionUK had several voluntary website designers. She would contact Charles to discuss. They could look at the possibility of someone developing a website free of charge.

6. NICE – ME GUIDELINE DEVELOPMENT

Charles Shepherd, Willy Weir and Tony Crouch were all members of the NICE Guideline Development Group and were limited in what they could say.

Charles stressed that this was going to be a completely new guideline. There had been many Zoom meetings during July and August and had made up the ground lost during lockdown.

A draft with conclusions and recommendations had been produced and consensually agreed. The draft would go out to Stakeholder consultation on 10 November and there would be a 6-week consultation period ending on 22 December.

If there was to be a Forward-ME response, Charles suggested the Group should meet towards the end of November. It was important that all stakeholders, as well as Forward-ME, should send in robust responses.

7. DECODE-ME

Charles Shepherd and Margaret Mar were both members of the PPI Steering Group. Charles said there was not a lot to add to what was said last time. There were discussions in progress relating to contractual arrangements. The contracts kicked in on 1 September and had to be agreed by 28 September.

Well over 20,000 people had already signed up to express an interest to take part in the research. Patient recruitment proper would start in March 2021. He would encourage all the charities to encourage expressed interest in the project. Not all those who signed up would be eligible to take part, so many more signatures were wanted.



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8. JAMES LIND ALLIANCE PRIORITY SETTING PARTNERSHIP (PSP)

Russell Fleming, who represents Forward-ME on the PSP Steering Group, said that everybody who had applied, and who were considered top candidates for the steering group, had now been accepted. There would be a meeting at the end of September to introduce them to the concept of the PSP. They have parents, carers, people with ME and clinicians including some very well-known names. Sam Bromiley said that it was a strong group and they were looking forward to starting work.

9. DEPARTMENT OF WORK AND PENSIONS (DWP)

Margaret Mar thanked Christine for the briefing she had sent to the Group.

Christine said that the DWP were going to continue with paper-based and telephone assessments during the current COVID19 crisis.

She would like to know whether there was any feedback on the awards for benefits and whether patients felt that they were getting the correct awards. Were telephone interviews preferable to face-to-face interviews? Were there more awards that were right the first time?

Russell Fleming said that throughout the COVID situation it had been incredibly quiet. They would normally have had several emails a week with problems in dealing with benefits, but he felt as if no one was applying for benefits any more.

Charles Shepherd had met with Maximus and the DWP where most of the discussion was on assessments and future proposals. Most of their clinicians had returned to the NHS frontline to deal with COVID19. This would explain the light touch.

Maximus were doing 10,000 telephone interviews per week. It was clear that for the near future there would be no assessment centres open. Every DWP assessment would be by telephone, though they were looking at Zoom. He did not get a satisfactory answer from the DWP when he asked why PIP assessments could not be completed online.

The ME Association had done a Facebook feedback request on telephone consultation before the meeting. Whilst there were advantages to not having to attend assessment centres, one big problem that emerged was that that people with cognitive function had difficulty with long telephone interviews and assessments. Maximus said that they could factor in a short break during an interview, but they did not have the capacity to insert longer breaks in interviews to enable people with ME to restore some of their energy. This was a major disadvantage to telephone assessments.

Christine Harrison said that Capita seemed to be more flexible. They had indicated that they would be willing to meet the Group if it would help.

Tony Crouch said that his daughter was only seen for about 20 seconds and the assessor was then happy for the rest of the assessment to be dealt with by her parents. He thought that should also be possible with telephone assessments. A carer or relative could take over the conversation, particularly for a person who was severely ill with ME. The PIP application should be signed by both patient and carer. There was concern that, after COVID19, there would be a flood of additional reviews for people with ME. Margaret asked for Catherine to inform Carol Monaghan of the discussion.



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Catherine said the next APPG meeting was going to be on DWP matters. She will be contacting Charles. Carol had submitted an Early Day Motion on Post-COVID symptoms and the similarities with ME. She is also going to write to the Secretary of State for Health and Social Care, Matt Hancock.

Willy Weir had been supporting ME patients with DWP applications, particularly when they were transferring from DLA to PIP. He was concerned by the assessors' apparent lack of knowledge of ME and the possibility that they were being paid by results. Margaret Mar told him that she had tabled questions in the House of Lords several times and had been assured that this was not the case.

Russell Fleming described the uncertainty that he had over getting a home assessment. He wondered whether there were any guidelines. Christine told him that, when the form PIP2 was completed there should be enough information to indicate/support the need for a home assessment. It would be helpful if a letter from a GP to support the need for home assessment could be attached. Everyone who required one should get one. It would be helpful if Carol could ask her MP colleagues what impression they got from correspondents of their experiences of assessments which were either paper-based or telephone and the levels of satisfaction with awards.

Note: See Addendum attached to the foot of these minutes from the DWP re: PIP and social support criteria.

10. RESEARCH

Margaret Mar asked Louise Crozier to report on ME Research UK projects. Louise would circulate a description of a current project. There was one project with Belgian researchers following up on a previous study of epigenetics. They had 8 grant applications which were being considered.

Charles Shepherd said that he and Charlotte Stephens of the ME Association attended the IACFS ME research virtual conference from New York. The MEA would be putting a conference report on their website. There was an interesting presentation from a Canadian group on the use of Low-Dose Naltrexone (LDN) for people with ME. Another US study on the detection of small fibre neuropathy which has links to the autonomic nervous system. This may be a clue to autonomic dysfunction in people with ME. He also announced that Willy Weir is to conduct a post-COVID19 study in conjunction with the ME Biobank.

Note: See Addendum attached to the foot of these minutes for MERUK research funding report.

11. STATEMENT ON SPINAL SURGERY FOR PATIENTS WITH ME

Russell Fleming was concerned that members of the public reading the proposed statement might not know what the surgery was about. Was it a big enough issue for everyone or did it simply concern a small number of people active on the internet?

Charles Shepherd said that there was a lot more interest in the USA where it had received more publicity. Professor Jonathan Edwards had approached several ME charities with his concerns. Small numbers of people in the UK were spending huge amounts of money to go overseas to have potentially unsuitable surgery. He felt it right that a group of charities, such as Forward-ME, should express their position on this. He suggested that we go back to Professor Edwards when we had decided on the wording of the statement as it was possible that some clinicians would also agree to sign.



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Sue Waddle said, in response to Russell's concerns, that there was a difference between fuelling flames and having a position statement. She had neck surgery in the past and had problems. It was a huge, life-changing operation.

Willy Weir described current evidence as anecdotal. He described conditions relating to the spinal cord and brain blood flow found in ME but cautioned against inappropriate surgery. He said that it was an area that needed to be thoroughly investigated rather than debunked. Margaret pointed out that the statement clearly indicated the need for scientific evidence.

Laurie Jones said that #MEActionUK also wanted to issue a statement but did not want to stifle exploration. People were getting surgery for co-morbid conditions. Doctors were not operating for ME symptoms. There was patient perception that surgery was for ME. It was people with co-morbid spinal conditions who were getting surgery. Margaret asked Laurie to make the necessary amendments to the statement.

Sam Bromiley said that AfME agreed with the statement in principle, but they would need two weeks to get their Trustees' feedback. He thought that this might give rise to questions about other 'fringe' treatments and wondered whether we need to take a position, or would this case be exceptional. He suggested that we should make a joint statement on CBT/GET.

Nigel Speight cautioned against being too negative. He had noticed the link between hypermobility and ME and others developed ME following neck injury.

Suzie Henson-Amphlett said that Tymes Trust would be happy to support the statement. Tony Crouch thought that the first sentence should be toned down. This was agreed.

Margaret said she would take any amendments and send the revised statement to the Group so that members could obtain Trustee approval where necessary. Agreement should be obtained by 30 September 2020.

12. ANY OTHER BUSINESS

Tony Crouch asked whether anyone had managed to contact Isabelle Trowler, Chief Social Worker for Families and Children. AfME had had no response to their request for her to sign off the information to help social workers to understand ME. He asked whether Carol Monaghan had had any contact. Catherine Frazier said that she had been written to but there had been no response. She would let us know when one was received.

Charles Shepherd suggested Professor Paul Garner, Professor of Tropical Medicine at Liverpool University, should be invited to join to us at our next meeting. He had been extremely critical of the current NICE Guideline for CFS/ME and he was also an editor of Cochrane. Margaret would contact him.

Simon Chandler told the Group that Clinical Commissioning Groups (CCG) AGMs were online, and questions could be asked of them electronically. They were obliged to respond. This was a facility much appreciated by ME patients. It could give rise to the appointment of an ME specialist GP for each CCG to whom other GPs could refer patients. He suggested all CCGs should be asked about their plans for long-COVID as they were likely to fit in with ME. Charles said there had been a File on 4 programme about post-COVID patients who had not been hospitalised. They asked CCGs what plans they had, and responses were dismal.



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Suzie suggested a Forward-ME letter that could be sent by the charities to CCGs so that all asked the same questions. Margaret would think about it. She asked member to contribute their thoughts and she would translate them into a letter for approval by the Group.

13. DATE OF NEXT MEETING

The next meeting would be in late November 2020. Date to be advised.
The meeting closed at 12.30 pm.

ADDENDUM 1: DWP & PIP

Christine Harrison (BRAME) received the following email from the DWP Personal Independence Payment (PIP) Team on 17 September 2020:

"The Minister for Disabled People, Health and Work (Justin Tomlinson MP) announced today the publication of an updated version of the PIP Assessment Guide (PIPAG) to reflect the implementation of the Supreme Court judgment in the case of Secretary of State for Work and Pensions v. MM into the Personal Independence Payment (PIP) assessment process.

"The Ministerial Statement can be found [here](#).

"This means that changes have been made to the way PIP Activity 9 is assessed, regarding the definition of social support when engaging with other people face to face and how far in advance that support can be provided.

- More information about [eligibility criteria](#) can be found on GOV.UK.
- A [Frequently Asked Question document](#) will appear here in due course.

"Claimants affected by the judgment awaiting a current decision do not need to take any action. The judgment will be applied to their PIP decision and they will be contacted if any further information is needed.

"We will be undertaking an administrative exercise to check whether claimants are entitled to more PIP as a result of the judgment. This is a complicated exercise and we are still planning our approach. We will provide a further update in due course."

ADDENDUM 2: MERUK RESEARCH FUNDING REPORT

Recently funded One project has recently been approved for funding to Prof. Jo Nijs and Prof. Lode Godderis at Vrije Univeriteit Brussel and the University of Leuven, respectively.

In a previous ME Research UK-funded study, they found that brain-derived neurotrophic factor (BDNF) was increased in ME/CFS, which is involved in sensitivity to pain. This new project expands on this, with a plan to investigate further the role of BDNF and histone deacetylases (HDACs), enzymes that are increased in neural sensitisation and pain, but have not been studied in ME/CFS. They plan to study this in the central sensitisation and post-exertional malaise experienced by people with ME/CFS, as well as the epigenetic changes occurring in these genes.



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Epigenetics is the study of genetic changes passed through generations, not from changes in the genes themselves but in regulatory factors involved in gene expression. Epigenetics has been linked to Alzheimer's and some cancers.

The investigators hope that epigenetic changes in BDNF and HDACs may provide a marker of ME/ CFS and potentially lead to new treatment strategies.

Applications in progress:

ME Research UK is currently evaluating eight applications for grant or PhD funding.



Countess Margaret of Mar
Chair of Forward ME



Carol Monaghan,
Deputy Chair of Forward ME
Chair of the APPG on ME
MP for Glasgow North-West



Dr Nina Muirhead
NHS Dermatology Surgeon
Chair of the CMRC Medical Education Group

Dr William Weir
Infectious Disease Consultant

Dr K.N. Hng
NHS Junior Doctor



Bill and Janice Kent
ReMEMber



Christine Harrison
BRAME



Tony Crouch
25% ME Group and Tymes Trust



Laurie Jones,
Managing Director, #MEAction UK
Denise Spreag

Natalie Hilliard
Dr Nicola Clague-Baker
Dr Michelle Bull
Karen Leslie
Physios for ME



Dr Charles Shepherd
Hon. Medical Adviser
Russell Fleming
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Dr Nigel Speight
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Sue Waddle
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Dr Paul Worthley
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