

Transverse Myelitis Society

Minutes of 6th AGM and 25th Meeting London Support Group 17th April 2010

At EC Harris HQ, 34 York Way, Kings Cross London N1 9AB

Attendees: Jean Anthony (Treas), Wilma Atherton, Barbara Babcock, Farshideh Bondarenko, Stewart Castledine, Sally Dray, Lew Gray (Secr), Ann Goddard, Peggy Hughes and Duncan, Al Ishmael, Yvonne Kolesar (Chair) and Simon, Therese Loh, Steven Malcolm and Carol, Ken Matheson, Cindy Morelli, Rob Reeves, Sally Rodohan (Pres) and Sean, Carmel Rodohan, Jayne and Paul Rose, Rupinder Sagar, Yasmin Sheikh, Roy Smith, Edward Taylor, Jackie Turberville and Brian, Debbie Weller

Apologies received from: Sue Bridge, Sheila Demery, Margaret Duggan, Ros and Adrian Gallagher, Nick and Ruth Heal, Michael Hutchinson, Sharon Livett, Jacqui Manning, Joanna Milne, Glen Palfrey, Paula and Malcolm Penn, Jack Pennington, Gill Rice, Jan Skillen, Barbara Teixeira

1. The Minutes of last year's AGM were approved. Yvonne Kolesar gave a brief Chairman's report reviewing 2009. Notable achievements over the past year included:
 - We had improved fundraising.
 - Dr Anu Jacob's TM research at Walton Centre continues.
 - We had a large increase in membership from 608 to over 750 (162 new members in the calendar year).
 - Thanks to Farshideh and Barbara Babcock, London meetings had improved in content and participation.
 - New Southeast Support Group had a good start. Unfortunately Mike Fishwick has withdrawn as Manchester Support Group Leader.
2. The Committee had decided to plan a 2nd UK TM Conference for Spring 2011. Volunteers were invited to join to help with preparations, either by joining the Committee or helping in other ways informally. The planning would start with a meeting of the Committee with all Support Group Leaders from around the country on Saturday 5th June.
3. Yvonne finished by paying thanks to Farshideh and Barbara Babcock for their tremendous efforts to help members individually as well as preparing for meetings, and for Lew Gray's continuing day-to-day efforts as Secretary.
4. Jean Anthony (Treasurer) presented the 2009 Accounts. Jean thanked all the members and well-wishers who had run races and jumped out of airplanes to raise money for the Society – as a result of everyone's efforts our income had doubled from £11k to £25k (excluding Rogers family fundraising)! We provided donations to Project Restore and Brain and Spine Foundation (Helpline) and also travel grants to assist families with TM kids to attend the TM Kids Camp and Johns Hopkins in USA. We had over £31k in the bank at the end of 2009.

5. Rob Reeves was retiring after 3 years on the Committee but was happy to stand for re-election. Rob and Barbara Babcock were nominated and seconded and elected to join the Committee. Additional positions on the Committee were still open if any member was interested to join.
6. Following the AGM, the 25th meeting of the London Support Group took place.
7. Farshideh gave an interesting presentation re postural control and balance working with her friend Peter from MedicoTech who had brought a very posh new standing frame and a Thera exercise bike (active+passive but not F.E.S.). Farshideh talked about balance: it is a combination of strength, sensation and eye positioning, also affected by habit (!) and reflexes ('toes up'). *Both* sides of the body must cooperate for good balance. Most TMers put too much weight on toes and they get curled; weight needs transfer back to heels. Sally and Rupinder volunteered for standing frame / balance demonstrations and Jackie Turberville came forward to try the Thera exercise bike.
8. Following a tea break (excellent refreshments provided by Yvonne), we all had a chance to update the Group or for new members to tell us about their experience with TM.
9. Stewart Castledine told us about his daughter (7) Kitty who had TM and was in intensive care for a while, now at Stanmore for rehab. Several people had comments to make about Stanmore, Dr Ming Lim etc. Stewart is determined to do whatever it takes to help Kitty recover. He was very impressed by the article in the TMA Journal (MacDonald/Becker) about neuro-plasticity and recovery. Doctors at Johns Hopkins have spoken to Dr Ming Lim about Kitty's case, and Dr Lim is organising plasma exchange for Kitty.
10. Barbara Babcock asked if anyone had any difficulty with general anesthetic. Lew Gray and Ken Matheson both had odd experiences. Ken made the point that anesthesiologists can always use a different anesthetic if they are told about a previous bad reaction.
11. Peggy Hughes said she was continuing to improve. She talked about the initial meeting of the new Southeast Support Group which was really good.
12. Rupinder said thanks to all the Group. He felt that he had benefited a lot from coming here at a previous meeting and hearing what people had to say.
13. Stephen Malcolm felt he had made almost no progress from first getting TM in November and pain was the main problem. He was back at work now and was given a new chair but he couldn't sit in it without pain so they gave him a new desk to stand at, instead.
14. Next meeting will be **Saturday 24th July 2pm at ECHQ**. The final meeting for 2010 will be 23rd October – but check on website in case dates change later <http://www.myelitis.org.uk/London/index.htm>