

The letter is now closed for new signatures and has been sent to the ME Association. If you'd like to be kept up to date with any response please sign up for emails here: <https://forms.gle/8pfWUmkLsWvmZqG86>

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To: ME Association Senior Leadership and Trustees
meconnect@meassociation.org.uk

Tuesday 18 November 2024

Re: Complaint about the Chairman's column: incorrect science, offensive content, language and tone

Dear ME Association

We are writing to you as patients with ME, carers, and health professionals. We were shocked and offended to read the editorial comment from chairman, suggesting that movement was required for improvement in ME.

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1. How was this comment allowed when it goes against everything we know about ME from the best science and research published and highlighted by your own team?
2. How was this allowed to be published? Do you not have a fact checking system in place? Did it not occur to anyone in the ME association that this could be incredibly offensive and potentially dangerous to a large cohort of patients who are struggling with severe ME?
3. How as a team do you continue to have confidence in your chairman when they present opinions such as this?
4. How was there no consideration for how those with severe ME would be impacted by reading this?
5. The columnist acknowledges (in a somewhat mocking tone) that this may cause complaints and yet, rather than present a balanced view, pushes on to overgeneralise from one person's experience as to what others should do, rather than basing their advice on science.

Not one of us shies away from maximising the movement we can achieve within the envelope we have, but for many people they don't have the privilege to rest or the privilege to be well enough to move at all. For some, the exertion of opening their eyes or digestion is too much.

Those who get better and improve in function are to be celebrated but surely we must also resist the urge to assign causation to correlation as in this case. Some people get better not because they decided to move. Rather, they got better, *then* they were able to move. We know from the excellent science and research summaries your team publishes regularly that

rest, not movement, is key to improving function. In time this allows movement to be reintroduced, but it's key that it's this way round.

We would expect this level of misunderstanding in the mainstream media, but to have to complain about it to one of the largest ME charities is rather sickening and upsetting.

We ask for a formal apology and retraction of the column and for your next editorial column to be written by somebody else with experience of severe ME, explaining the science about why movement must be introduced very carefully and PEM avoided at all costs.

Kind regards,

1. Alexis Gilbert FFPH MPH MBBS BSc (Severe ME, Long covid and POTs patient)
2. Frances Haddock BVSc MRCVS (Severe ME patient)
3. Sarah Boothby, Exeter
4. Persephone Pickering BSc (moderate/severe ME patient)
5. Arash Afazadeh
6. Lillian Hickey
7. Carrie Anna McGinn, MSc (co-president of the Association québécoise de l'encéphalomyélite myalgique; ME and Long COVID patient)
8. Anne Hall MSc MSc BSc
9. Jenny Spencer (Mother whose daughter died while bed bound)
10. Emily Schultz
11. Sally Doherty (Severe ME sufferer for 19 years and author who currently donates 10% of her book profits to the ME Association)
12. Tamara Barker
13. Carly Welton (severe ME patient)
14. Franziska Podesser Msc
15. Emily Miller
16. Michael Natt
17. Andrea Reynolds (Moderate ME patient)
18. Emer Duffy
19. Ollie Firestorm
20. Natalie Kimble
21. Sarah Hennell
22. Mr & Mrs Paul van Dyck (severe ME daughter - caused to become severe due to failure of psycho-social model to understand PEM)
23. Hannah Avery (Severe ME patient)
24. Ry Gibson Moss BA(hons) MSc
25. Helen Leonard-Williams
26. María Richardson (ME patient)
27. Emma Wooller (ME patient)
28. Nadine Wilkus (Severe ME patient)
29. Jamie McMahon
30. Julie Barlow
31. Theo Walker
32. Lindsay Gutierrez
33. Sophie Enever

34. Kerri Page
35. Li Karpuk
36. Henry Anderson (ME patient)
37. Maya Lindemann, RN (Severe ME patient)
38. Kathryn S McClelland, BSc., PhD (partner of an ME patient)
39. Greta Granö (Severe ME patient)
40. Arianne True (Severe ME patient)
41. Hayden Krause (Severe ME patient)
42. Dr Jo Greer (Parent of a Severe ME patient)
43. S. Hollis Mickey (Severe ME patient)
44. Elizabeth Mooney (ME patient)
45. Emily Marie Purvis (ME patient)
46. Ana LoCascio (ME patient)
47. Charisma Luke (Severe ME patient)
48. Sar Gavin (Friend to many with mild or severe ME or ME/LC, & ME patient)
49. Lau Gray (ME patient relative & friend)
50. Samm Hamm (ME patient)
51. Raquel Esther Parackal BBiomedSc BSc BMedSci(Hons) (Severe ME and LC patient)
52. Dineo Moja (ME patient)
53. Grażyna Wiśniewska-Rees (parent of severe ME)
54. Julia Hargesheimer (friend of a severe ME sufferer)
55. Marek Wilkus (father of a severe ME patient)
56. Hollie Bramwell (ME patient)
57. Taylor Ryan (Severe ME patient)
58. Rowan Clarke (3 years ME/CFS)
59. Karen (ME patient for 26 years)
60. Julia Fitzpatrick BSc (ME patient)
61. M. Brice (ME patient and advocate)
62. Maya Gibbon BSc(Hons)PGCE (severe ME and LC patient)
63. Erika Kiviniitty (severe ME patient)
64. Emily Fraser (severe ME and LC patient)
65. Carly Hearn (severe ME patient)
66. Mirjam Denhoff (moderate to severe ME patient)
67. Lala Novali (Moderate to Severe ME and LC patient)
68. Elizabeth Bassnett (Retired Counselling Therapist, Severe M.E patient),
69. Kelly Alger (ME patient)
70. Rachel Spading
71. Shanna Sonnier (5 years ME/CFS)
72. Dr Claire Shepherd PhD, BSc (Hons), (moderate ME/CFS)
73. Dr Rebecca Williams MbChb Bsc DCH (severe ME and long covid patient)
74. Brighid Ó Dochartaigh (Moderate LC/ME patient)
75. Milla Tengström (Moderate to severe ME patient, Social Psychologist).
76. Jessica Thompson (ME patient)
77. Fiona Hart
78. Sam Caton PhD, M.Med.Sci, BSc (LC/ moderate ME)
79. Dorota Oakley Matuszyk MSc (ME patient)
80. Louise Martin (Severe ME & LC Patient)

81. Marketa Stikarova (LC patient)
82. Ellen Cliff MRes Oxon (severe ME patient)
83. Jay Hebblethwaite (severe ME patient)
84. Dr Jane Macaskill, MBChB, MD, FRCSEd
85. Chris Parkes (moderate to severe ME patient - ex MEA member)
86. Jaimie Pattison (Moderate to Severe ME 46 years)
87. Ridah Jamil MPharm - (moderate ME/CFS patient)
88. Sam Pearce MPhil (ME 34 years)
89. Mlinden Gabela (LC 5 years)
90. Bettie Hough (ME 24 years)
91. Thérèse Fensham (ME 25 years)
92. Róisín Keogh (severe ME patient 5 years)
93. Sarah Thomas (Severe ME patient 7 years)
94. Dr Rosanna M Wregor (caregiver to Severe ME, ex MEA member)
95. Alan Allister (very severe ME patient, ex MEA member)
96. Alicia Pallenchier (Master's in Health Law / Health Law jurist - France, very severe ME / LC patient)
97. Dr Rosemary Haddock MBChB MRCP PGDip (sister of severe ME patient)
98. Katie Ash (person with severe ME)
99. Giovanni Manderioli
100. Emily Rose I (severe ME/LC patient)
101. Dr Ray Haddock MBChB, FRCPsych (Carer for ME/LC person)
102. Penny Hassack (severe ME patient 31 years)
103. Sylvie Jourdan (ME patient, 10years)
104. Laura de Vries MD, PhD (moderate/severe ME patient for 7 years)
105. Katryn Bradford (ME patient, 8 years)
106. Nicola Knox (ME patient)
107. Nea Lundell
108. Sara Westrop (ME patient)
109. Derrick Cunningham (friend of severe ME patient)
110. Paula Knight (bedridden 6 years)
111. Karen Galpin (carer for very severe ME patient)
112. Caroline Fricker (carer for a very severe ME patient)
113. Frances Camilleri (friend of a very severe ME patient)
114. Alice Fricker (Very severe ME patient of 9 years)
115. Hugo Mispelhorn (severe ME patient)
116. Jamie Smith (10-year ME patient who went from severe to moderate through total bedrest)
117. David Tyrer (ME patient for 6.5 years)
118. Charlotte Green (ME patient for 13 years)
119. Kirstie Sivapalan (ME for 33 years)
120. Jessie Lawson (Moderate to severe LC patient)
121. Socrates Pyliotis (Moderate to severe LC patient)
122. Daniel Moore (Former MEA champion blogger and host of Post Exertional Mayonnaise podcast)
123. Sharon Benton (parent and carer of 2 sons with long covid/very severe ME)
124. Julie Newson (ME for 26 years)
125. Lucy Montgomery (carer of daughter with very severe ME)

126. Paul Keeble (Severe ME, 8 years)
127. Joanne Smith (ME for 33 years)
128. Suzy Chapman (advocate, carer of adult with ME for 26 years, owner of DxRevisionWatch)
129. Tess Seren Hillier (ME for 15 years, registered nurse for 40 years until too sick to work) Mild initially, progressively worsening to very severe and bedbound.
130. Rich Benham
131. Naomi Benham (parents of recently diagnosed)
132. Jennifer Bossi (v severe ME patient)
133. Tina Rodwell
134. Anne Dean (Have had ME for 34 years (quite severely affected last 10 yrs)
Constantly trying to improve my health. But so many things cause me to crash (eg, pushing myself too hard against symptoms)
135. Linda Hending
136. Rashmica Gupta (mild/moderate LC/ME)
137. Jackie Rounsley (Parent of Severe ME daughter)
138. Monica Dalby
139. Lynne Blakey (daughter damaged by GET)
140. Sally
141. Hannah Boyland (Moderate ME patient)
142. Philip Youngs (various degrees of ME for 20 years, cofounder of Mutual Aid For ME, movement my biggest trigger)
143. Roos Valk (various degrees of ME for 20 years)
144. Katie Anderson-Morrison (Moderate ME patient)
145. Carol Youngs (parent, fundraiser and part time carer of Philip)
146. Derek Youngs (parent and full time carer to Philip)
147. Katy Bruce (severe M.E 39 years)
148. Claire Higham
149. Agnieszka Popowicz (friend of Severe ME patient and 5th year medical student)
150. Claire Naylor (ME 15+ years)
151. Janet Hassall B.Ed, M.Ed - 74 years old - severe spinal stenosis - moderate to severe ME for 5 years - housebound - live alone. ME caused by stress, as far as i can tell around PIP benefit.
152. Laura Brockway (Severe ME 11 years)
153. Sharon Brockway (parent of daughter with Severe ME)
154. Verity Harris (sibling of a Severe ME patient and Disabled Students Representative for Northumbria University)
155. Elizabeth McCutcheon (mild/mod ME - diagnosed 10 years, sick since 13 y/o, child of a former severe ME patient).
156. Terry Field (severe ME, 33 years)
157. Katarzyna Pollock (Moderate ME since 2014, severe ME since covid infection in 2020)
158. Felix Pollock DPhil (Moderate ME and LC patient)
159. Andrew Gifford (ME 10-30 years, lower-severe, housebound, unable to work)
160. Sara Schwalm (mild ME/LC)
161. Jean-Marie Stewart (ME Patient)
162. Darlene Dech (ME patient)
163. Ella Pawlik (ME for 12 years)

164. Dan Wyke (severe ME, 14 years)
165. Olivia Hoare (Occupational Therapist, now severe ME for 4 years)
166. Dr Naomi Harvey, ME for 22 years
167. Julia Lamb Tod (M.E. Patient 24 years)
168. Carole Bruce
169. Lee Suddaby (very severe ME patient)
170. Alison Williams (severe ME patient)
171. Geraldine O'Sullivan-Hogan
172. Julie fitch (ME patient)
173. Sarah Weston RD
174. Maddy O'Brien (ME patient for 13 years)
175. Tom Molmans, MD (moderate/severe ME due to Covid)
176. E. O'Shea (friend and family member to multiple people with LC/ME)
177. Elizabeth Moore, ME for 9 years
178. Dr Olivia Beatty MD MRCP
179. Elin Curtis
180. Anne-Maarit Saaranen (severe/very severe ME patient)
181. Clare Norton (mother and carer of Merryn Crofts, Very Severe M.E patient who died of M.E aged just 21)
182. Julie Houston (ME patient, 26 years)
183. Julia Lamb Tod (ME patient, 24 years, now severe)
184. Emma close mum to daughter 18 very severe ME 6 years
185. Claire Hawk (ME patient, 15 years, mild became moderate)
186. Latisha Shuff, ME patient 5 years
187. Niko Suvisto (severe ME patient)
188. Natalie MacWilliam (ME patient 20+ years)
189. Pamela Stocks (ME patient 50+ years)
190. Anna wood (ME patient 24 years)
191. Colin Vallance (carer of ME patient of 26 years)
192. Max Nits, 17 years of ME, movement made me homebound
193. Asta Wright (ME patient)
194. Maria Moore (Severe ME 36 years)
195. Lucy Ainsley (patient 30 years)
196. Chris Bell (ME patient 12 years)
197. Alison Nolan (ME patient)
198. Traci Donatto (ME patient, 16 years; made homebound, then bedbound by exertion)
199. Kim Matthews BSc (moderate ME patient for over 10 years)
200. Lorna McKay
201. Bryce Goodall - Disabled Person
202. Kaptain Spikey Kw
203. Mimi Tate (ME patient for 5 years)
204. Dr. Sujana Reddy, DO (moderate ME patient for 5 years)
205. Kim Foster (moderate-severe ME)
206. Dr. Kaiden Price (neuroscientist, moderate ME patient for 2 years)
207. Kayleigh Paske BSc
208. Paulina Brown (RN for 15 years, severe ME for 2 years)
209. Samantha Crausman, severe ME patient

210. Jacqueline Ferreira, ME/CFS patient for 35 years
211. Claire Bowler BA (Hons) long covid and suspected ME patient
212. Sophie McCallum (ME patient for 4 years)
213. Christine Sweeney (ill for 23 years and now severe, due to overdoing my movement)
214. Joanna Livingston
215. C Lucassen (severe ME patient for 3 years, mild and moderate before)
216. Elizabeth Morrison Ba(Hons), PGCE (officially diagnosed with ME for 5 years)
217. Elisabeth Klaar
218. Louise Rainbow. (Very severe ME 10 months)
219. Laura de Vries MD PhD (ME patient for 7 years, now moderate/severe)
220. Jeanneke Van Roeyen (severe/very severe ME)
221. Rita Greenway Severe ME for 7 years
222. Jane Wingfield (have had ME for well over 20 years)
223. Fen van Rhijn MD (moderate ME after covid since 2022)
224. Chloé de Canson PhD (severe ME for 2 years)
225. Gosia Furmanik, PhD (moderate ME patient for 2 years)
226. Pamela Du Val
227. Megan Lee, (moderate-severe ME patient for 14 years)
228. Aimee Love
229. Hayley Scott (BSc Hons) (severe ME patient)
230. Amanda St Clair - moderate/severe ME patient for 2 years
231. Zoe Walker
232. Ryder Phoenix
233. Cyndi Geoghegan MB BChir DPhil (medical doctor and severe ME patient)
234. Holly Campbell, ME/CFS 12 years
235. Erin kenny
236. Katie Johnstone BSc (moderate ME for 14 years)
237. Helenproudfoot1@gmail.com (pwME for 4 years)
238. Michelle Nye severe ME patient for 15 years
239. Ian Nye carer of severe ME patient of 15 years
240. Christina Baltais (ME patient 19 years)
241. Rosie Jones (ME patient 12 years)
242. Matt Lazell-Fairman (ME patient, 14 years)
243. Tracy Meggitt (ME 10 years, Severe ME 2 years)
244. Gillian Wright ME patient
245. Emily Lawton (ME patient)
246. Michelle Bowman MA (severe ME patient)
247. Katarzyna Borhardt (ME patient)
248. Peter Hutchison (carer for very severe Long Covid ME patient)
249. Katie Dermody, MLIS (ME patient for 6 years)
250. Nicola De Boo (ME for 21 years, the last 6 severe)
251. Alison Thomson
252. Jennifer Hay (ME patient for 10 years)
253. Katy Wimhurst (ME patient for 25 years)
254. Maud (severe ME)
255. Imogen Wescott MA MSc
256. Chrissy Mondson (My niece has severe ME)

257. Ellie Mullis (ME sufferer of 10 years)
258. Joanne Oliver (ME 6 years known)
259. Emma Parkinson (Moderate/Severe ME Patient)
260. Becca (Lavender) Thomas (Moderate ME Patient)
261. Julie Lewis (severe ME)
262. Christopher Spalding (moderate ME patient)
263. Jonee Lillard (MS2)
264. Alyssa Nagassar, MScPT (ME, long covid)
265. Andrea Brown (disabled by ME since 2019)
266. Sandra Hughes (ME sufferer for 37 years)
267. Jess Badger (scientist, 20 year ME patient, currently bedbound)
268. Nicola Zussman
269. Stephanie Stott (moderate-severe ME/CFS for 8.5 years and sufferer of 22 years since age 11)
270. Alison Benfield BA (bad ME patient for 4 years)
271. Jill Hughes (diagnosed ME/CFS patient)
272. Margaret Keen, MsED (moderate ME/LC patient)
273. Beth woodburn
274. Heini Kekki (severe ME/LC patient)
275. Russell Oliver
276. McLaine White
277. Jo Claire Burkett Mitchell
278. Megan Shepherd
279. Jennifer Stitt
280. Jade Brown MA (carer for ME patient)
281. Jackie mracek (moderate ME)
282. Sophie Delhaes (moderate ME for 14 years)
283. Claire Underwood (ME for 2.5years)
284. SSunniva Innstrand (sick with ME/CFS since 2018)
285. Dr Lydia Dodd MBChB(Hons), BNurs(Hons), MPhil(Psych), MRCGP(2017).
(Severe ME)
286. Jessica Donley
287. Emma Knight, Parent to housebound ME patient.
288. Katherine Baldwin BSc (ME/CFS for 20 years)
289. Ruth Jones (moderate patient for a decade: declined seriously after having the same advice from doctors for 5 years. If I had rested and paced I may well not be housebound and be able to continue to career I loved)
290. Kari Elizabeth Olivier (severe ME patient)
291. Katie Proctor
292. Violet Williams (ME patient for 7 years)
293. Lynn Ball (severe ME patient for 20 years)
294. Kathryn Chaffin
295. Eleanor Daniels MSci (severe ME patient)
296. Jannik Mebus (severe ME patient; My brother died of very severe ME, not because of tiredness.)
297. Chloe Williams, PhD (ME patient)
298. Dr Helen Williams (Clinical Psychologist & severe ME patient)
299. Imogen Hobson

300. Steve Fifield (ME for 14 years)
301. Kitty Parker (ME/CFS patient for 48 years)
302. Annie Wright (ME patient)
303. Maria Sale (ME patient for 32 years)
304. Anna Parker (severe ME patient)
305. Graeme Murray CEng (ME patient for 7 years)
306. Kerri Page (ME patient of 10 years)
307. Carol Freeman MSc MPhil (mother & sister of women with ME)
308. Angela Sinclair Millar (Severe ME patient)
309. Flora Fricker (Sister of very severe ME patient)
310. Ema Holt (Moderate/Severe ME; started mild>20yrs ago, didn't rest, now housebound)
311. Malaika Erasmus (severe ME, Covid induced in 2020, house and bedbound)
312. Christine O'Neill (moderate/severe ME, Covid-induced April 2023; pushed through symptoms, now housebound and bed-tethered)
313. Amy Walker (BSc honours in Mental Health Nursing Moderate ME patient)
314. Andrea Powell (Mild ME 2010 to 2015 - kept moving and didn't rest, ended up with Severe M.E from Xmas 2015 to date, guessing the, 'not stopping moving' didn't work for me.
315. Eleanor Marsh - moderate/severe ME.
316. Isabella Fricker (Sister of very Severe ME Patient.
317. Dan Swinhoe (friend of a very severe ME patient)
318. Monika Daszczuk (friend of a very severe ME patient)
319. April Bixler (severe ME patient)
320. Rebecca Hams (ME patient for 24 years)
321. Yann Kull (very severe ME)
322. Owen White
323. Tina Horton, moderate me for 4.5 years
324. Ita Watterson
325. Sue Worrall BSc. (Moderate to severe after viral pneumonia in 1997. Volunteer in running a local ME group for 20 years. GET confined me to bed and lost me my career).
326. Linda Sanday (chronic fatigue)
327. Heather Benfield
328. Karen Renton (ME for 18 years)
329. Dave Stott (carer for moderate/severe wife for 7 years)
330. Jane Howick (ME patient for 20 years)
331. Sharon Askew
332. Rochelle Boaden
333. L Hopwood (ME since 2013)
334. Thomas Franz (ME for 10 years, severe ME for 4 years)
335. Whitney Fox (person with ME)
336. Lucid Drysdale (Severe ME patient for 5 years. Went from Mild to Severe extremely quickly & experienced 2 years of upper body paralysis from pushing through symptoms.)
337. Abigail Gilchrist (severe ME for 6 months, moderate/mild ME for 5 years).
338. Helen Matthews
339. Deborah Riley (Son has progressive had ME 15 years)

340. Andrea Hams (mother & carer to daughter with ME)
341. Kirsty Roberts (mild ME 11 years, 13 year remission, 6 year severe relapse)
342. Craig Griffin (partner has had ME for 24 years)
343. Kimberley Potter (ME sufferer)
344. Rachael Ferrera (moderate/severe ME patient for 1 year)
345. Emma martin
346. Michael Nobbs BA MA (diagnosed with ME in 1997)
347. Robert Saunders (Severe ME/CFS since 1992)
348. Ann West BArch, Dip Arch, BSc (Carer of daughter with ME)
349. Phillippa Holland (patient for over 14 years)
350. Peter Trewhitt MA MSc DipCCS (ME patient 30 years)
351. Agnieszka Leszek (ME for 14 yrs)
352. Mari Milkie (ME for 14 yrs, severe for 1)
353. Ella Alexander BA LLBo
354. Portia Zar
355. Sophie Stanbridge
356. Claire Huntley BSc (ME patient for 30 years)
357. Lauren Pettit
358. Madeleine Marsh (severe ME patient)
359. Sebastian Sto
360. Victoria Göske MA political scientist (severe ME patient for three years)
361. Alice Gibson (ME patient)
362. Emily Johnson (ME/CFS patient, medical journalism, medical researcher)
363. Samantha Radaelli (Partner has ME)
364. Michiel van Zanten (ME for 10 years)
365. Alexandra Oliver
366. Cara Marshall (ME patient)
367. Mandy Kokani (ME patient)
368. Saeid Kokani (carer)
369. Dr Asad Khan FRCP FRACP (LC and ME patient, advocate & researcher. Parent of child with LCME. Son & sibling of LCME sufferers)
370. Jessica Taylor-Bearman
371. Cathryn Worrell
372. Sarah Richardson, Mother of ME patient
373. Nikki Gaines (severe ME patient-sick 12yr)
374. Tara Mills BSc DPhil (worsening ME for 7 years)
375. Katharine Kane
376. Emma Barnard
377. Sara Graybow (carer for severe ME patient)
378. Emily McGregor (severe ME patient)
379. Emma Young (severe ME patient for 3 years, now moderate)
380. Mariette Steltman
381. Laura Beckman (mild ME patient)
382. Anne Robertson (ME - 16 yrs)
383. Hannah Bada (ME patient)
384. Elaine Levett (ME for 18 years)
385. Louise Metcalf (ME since 2017. Gradually worsening - now on lower end of severe)

386. Eddy Iwanczuk (carer for family member with ME)
387. Nadia Wright (ME patient 10 years)
388. Siele Rombaut (caregiver)
389. Lizzy Horn (Severe ME patient)
390. Lissa Walton (Severe ME sufferer)
391. Sylvia Moyes (moderate ME patient)
392. Heidi Connahs (Severe ME since Covid March 2020)
393. Laura Houston (daughter/carers to Mum with ME)
394. Judith Remkes (ME patient, 14 years)
395. Lynda McEwan (ME patient 24 years)
396. A Wright (ME patient)
397. Matt Dobson friend of ME sufferer
398. Elina Skoogh ME sufferer
399. Tobias Schweikert ME sufferer
400. Nick Greer (Parent of Severe ME patient)
401. Ann Marie McConnell
402. Phil McConnell
403. Ashe Abbott DiBlasi (patient, 20 years)
404. Jess Mossman-Smith
405. Catriona Macdonald (me/cfs patient)
406. Catherine Hale (ME/cfs for 35 years)
407. Rebecka Slater Lyons (wife of ME sufferer)
408. Andréa Andersson (severe ME, 9 yrs)
409. Dom Salisbury PhD (ex-member, CMRC/MERC Patient Advisory Group)
410. Catherine Romatowski (ME since 2005; 99% bedbound with v. severe ME since 2019)
411. Aaron Thomas (ME induced by Long COVID for 3 years)
412. Lee Palmer
413. Beckie Smith (moderate ME patient)
414. Tom Seeler (severe ME for 5 years, post covid)
415. Amy Hanson severe ME patient. Sick for 25 years.
416. Victoria Boyling BA(Hons) PGCE Sufferer for 4 years
417. Melanie Sapiets carer for Severe ME patient
418. John Karley
419. Kelsa Rowland-Evans
420. Phil Prydderch BSc MCIWEM (Mod/Severe ME 6 years)
421. David Richards BSc ME patient getting worse over 12 years
422. Bryony Graham (ME patient)
423. Charlie Roberts
424. Sonya Greenawalt, severe ME patient
425. Dr Peter Handy PhD MEng(Hons) CEng (Mild ME patient for 18 years / Severe ME Patient for 2 1/2 years)
426. Pete Tomkinson
427. Katy McLean, severe ME patient 18 months, moderate ME patient 3 years
428. Gracie Forder ME patient since 2015
429. Kate Belska
430. Athena Czerwinski, BS (long covid patient)
431. Dan Kenny BVSc CertAVP(GSAS) MRCVS (carer for someone with severe ME)

432. Mrs Katharine Mathews BA HONs (carer for child who has had ME for 17yrs & suffer myself for 13yrs).
433. Jenny McGibbon
434. Áine O'Hara
435. Sean Stidston (patient for 14 years)
436. Phoebe Wilkins - Severe M.E. patient for 16 years.
437. Lottie Slater-Brown
438. Jessica Meehan
439. Amy McRae (pwME)
440. Zoe Thorp BVetMed (moderate-severe ME for 7+ years)
441. Carol John
442. Portia Zar (housebound pwME)
443. Carol John (severe ME patient for 6 years)
444. Jennifer Huff (ME patient since 2019)
445. James Higginbottom (full time carer and husband of someone with severe ME and LC)
446. Alice B Gardner-Bates (moderate ME 25 years)
447. Bridie McLean (severe ME patient)
448. Venke Midtlien (ME patient for 28 years)
449. Rhiana Lewis
450. Rebecka Johnfors (mild - very severe pwme for 16 years)
451. Taryn Marquez
452. Yazlin Estrada Gallegos
453. Zoe Fear (ME sufferer for 4 years)
454. Giles Meehan, M.A M.Eng (Cantab), "Get well from M.E" video blogs
455. Poppy McRoberts (mild to moderate ME sufferer for 15 years)
456. Dr Julia Langley
457. Vanessa Rose
458. Paul Komoroski
459. Hope Whitestone, BS BME. (My mother, sister and I have had ME for over 10 years).
460. Laurin Milsom (LC/ME patient for 2 years)
461. Kim Clugston
462. Tara McElduff
463. Melinda Lipscomb (Severe ME patient)
464. Danielle Green (Long Covid ME patient)
465. Olivia Scott-Berry
466. Laura Pettenuzzo
467. Valerie Ann Pedrick Moderate (ME 12 years, worsened by GET)
468. Sian Bedford
469. Harriet Carroll, BA MSc MRes PhD
470. Ivan Gerardus Adrianus Langen, (ME patient for 10 years, moderate for 3 yrs.)
471. Amanda Sarellas (ME patient for 2+ years)
472. Vivienne Gilchrist (moderate/severe ME patient for 21 years)
473. Nicolette Mansour
474. Nora Cabrera
475. Sean Kirby
476. Cara Bentrup (housebound ME/CFS sufferer)

477. Kirsty Hall (ME patient for 29 years, currently moderate)
478. Melanie Foulkes MCoun (ME patient 6 years)
479. Mallory Stanislawczyk MSN, Pediatric Nurse Practitioner, ME patient of 3 years
480. Valerie Sadler (ME patient for 27 years)
481. Alaa Hijazi, PhD. (Clinical psychologist)
482. Michele McKeever (ME for 27 years, severe for 8)
483. Peter Wiggins BSc Hons (severe Long Covid patient for almost 4 years and Functional Neurological Disorder patient for 1.5 years)
484. Annie Smith (BPSc; BOT)
485. Kayla Zwicker
486. Luci Camorani (ME patient for 11 years)
487. Beth Dobbin OLY (ME for 2 years)
488. Christina Taylor Bsc honours (semi severe - moderate ME patient)
489. Carrie Anna McGinn
490. Ava Gartner BSc
491. Kyra Miles
492. Ramelle Carroll (severe ME patient, bedbound 3 years)
493. Zahraa Frag (person with ME)
494. Charlotte Rogers
495. Kirsty Phillipson-Lowe (LC 3 years/CFS/FND/Fibro)
496. Harald Krisner (parent for 3 heavy sick children over 20 years and partly recovered)
497. Ina (severe me for many years, sick for 20 years)
498. Ola Pedersen
499. Zoe Llewellyn (retired nurse)
500. Katie Ash
501. Helen Gibson (carer of a daughter with severe ME)
502. Helen Stout, BSc Hons (Severe ME for 4 years)
503. Kate Skilbeck (moderate ME)
504. Tone Bakkevold. (I have two family members with ME)
505. Zaya Fullerton MSc BSc
506. Andrew Flewitt Bsc(Maths) (Artist; moderate-severe M.E./P.OT.s patient for 25 years)
507. Sarah Hannant
508. Megan Pendleton (Severe ME patient for 6 years)
509. Katiana Mekka, former Msc student (Severe ME patient for 3 years)
510. Claire Allport (ME/POTS since childhood, currently severe)
511. Dee Edwards
512. James Foulger
513. Barbara McLaren (Severe ME)
514. Juan Palma Gutierrez (Severe ME 30 years)
515. Kaitlin Williams MA (ME patient)
516. Frøydís Lilledalen
517. Cleo Scrivener (ME patient for 11 years)
518. Morgan Gilbert
519. Jane Macey, Artist (Severe ME for 4 years)

520. Dee Montague-Coast, (ME Patient, Patient Representative for ME on the Women's Health Wales Coalition)
521. Jessica Whetstine (Severe ME patient - Bedridden for 10yrs, after following medical advice to try to keep moving)
522. Lily Ickowitz-Seidler MSc BSc (mild ME patient for 24 years)
523. Dr Helen Moore (MSc, MA, PhD).
524. Ilse Groot MA BSc
525. Hannah Eaton
526. Tracey Thompson (Moderate/Severe ME 5 years)
527. Elina Hagen
528. Martha Gail Moore (ME patient for 15 years)
529. Kerry Newnham
530. Cynthia Rittersma
531. Anon (Patient for 30 years)
532. Vivian Roode EngD MSc (severe ME patient for 4.5 years)
533. Naomi Whittingham, A Life Hidden (severely affected for 35 years)
534. Miss Miriam Dyer
535. Vikki Cau BSc MSc
536. Tori Tijan
537. Halima Ahmad
538. Eleanor Davin, (person with Severe ME/CFS 11 years)
539. Dina Christophersen (ME patient for 15 years)
540. Andrew Scott (LC/ME patient for 2 years)
541. Jenny Sullivan (Long Covid and ME/ CFS patient, former teacher)
542. Amanda Shortman (Me/CFS patient)
543. Dr. Anja Karina Nydal (M.E patient 5.5 years)
544. Aiyla Syed (friend of v.severe ME patient)
545. Jen Wandel (healthcare professional for over 15 years, ME for 2 years)
546. Kate Everson (ME patient for 3 years)
547. Sara-Jayne Slack (carer for severe ME wife)
548. Laura Cayuela Ferrero (severe ME, 3 years)
549. E J Skeates (ME 22 years)
550. Louise Palmer BMus MA (moderate To severe ME patient for 15 years)
551. Ren Fraser (ME patient for 17 years - 7 of which were severe)
552. Dan Coast
553. Caroline Day (moderate M.E. patient of 15 years)
554. Michelle Sarsfield (severe ME patient)
555. Leonie Potgieter (ME patient)
556. Kyle Hudspeth (carer for partner with ME for 3 years, currently severe)
557. Sergio Perez PhD (Mathematics), MSc (Health Psychology)
558. Natalie Morris-Webb BVSc MRCVS CertAVP SAM
559. Luke Yeates BVSc PgCertVPS (friend of a patient with severe ME)
560. Daisy Dunne (Person who has experienced severe, moderate and mild ME for nearly 10 years)
561. Alex Winter BVSc MRCVS (friend of person with severe ME)
562. Kate Green BVSc MRCVS (friend of person with severe ME)
563. Teresa Pinto
564. Pia Frank (ME/CFS patient for 10 years)

565. Marion McDonald
566. Lexi Boreham (Long Covid patient and ME advocate)
567. Richard Green (ME patient for 2 years)
568. Alice Pinto (healthy family member)
569. Ona Albizu PhD MSc /mod-severe ME patient for 35y
570. Enrique Lorente
571. Nuria Ruiz Sebastian
572. Dr A. Davenport
573. Sara Waterhouse (mum to daughter with moderate ME for 5 years)
574. Donna (ME patient for 14 years)
575. Dr Susan Braddock
576. Chloe Gray
577. Anne Zimmerbeutel
578. Matilda Travers
579. Cornelia Turner
580. Diane Gilbank severe ME 36 years
581. Julie Ritchie (29yrs ME)
582. Katie Packer BSc, former SCPHN.
583. Dr Ashley Fisher (ME patient for 3+ years and disability activist)
584. Karen Shaw BSc Physio
585. Stefanie Weissensteiner, MA MSc BA (severe ME patient for 2,5 years)
586. Lauren Howe Bsc (Moderate ME for 3 years)
587. Victoria Langer (former passionate rock climber, now in a wheelchair, ME for one year)
588. Beatrice Elliott BSc
589. Georgie Wishart
590. Nicky Austin
591. Annie Warner (ME patient)
592. Helen Dawes MA(Cantab) (4.5 years ME sufferer)
593. Gemma Northover
594. Carol Binks: (ME patient 17 years; (Parent of ME patient)
595. Carole Pearce (parent of ME patient)
596. Ashley Timms (Moderate/Severe ME patient)
597. Sonia Monette (ME patient for 8 years)
598. Zoe Clayton BSc (ME for 15 years)
599. Rachel reaveley MBBS, severe ME/CFS 2.5 years
600. Jessica Wambeek BSc (moderate ME for 4 years)
601. Tom Parsons (severe ME 4 years)
602. Chey Paisley (Diagnosed in June 2024)
603. Katie Roberts (severe/very servers ME patient for 4 years, ME for another 3)
604. Phiz Carter (Moderate ME patient for 10 years)
605. Stella Leinonen LLM (severe ME patient for 2 years)
606. Red Yates (daughter of a severe ME patient who was dealing with this sort of rubbish back in the 90s - how has nothing changed?!)
607. Maïa Vinçonneau
608. Alexandra Frink (Long Covid /ME since Christmas 2023)
609. Barry Chapman (parent of adult child with ME for 26 years)
610. Rosanne Sliuzas

611. Megan Walker MSc (CFS patient for 2 years)
612. Kathrin Leuchs (Psychotherapeutin, ME Patient for 2 years)
613. Alexander Burbaum
614. Emily Shaw
615. Wayne Blackshire (moderate ME 21 Years)
616. Hayley Cotter LLB (moderate to severe patient for 10+ years)
617. Jennifer Readings (Long covid for 3 years)
618. Katherine Linsley
619. Abbie Proffitt (Bsc Hons) (Nurse living with long covid for 2.5 years)
620. Lucy Foot
621. Louise England BSc MSc (LC/ME patient 2 years)
622. Clara Golzarmanesh (healthy ally)
623. Jackie Sutherland
624. Keja Ogden (ME for 10+ years)
625. Coralie Blunier MA
626. Harriet Godfrey (ME patient for 2 years)
627. Sabrina Poirier (ME and comorbidities for nearly 17 years)
628. Kiki Grinwis
629. Laura van der Weert (long covid patiënt for 1 year)
630. Kim Ammons
631. Alex Garrick (ME sufferer for three years - many of us really struggle to sacrifice movement we once loved (for me long walks in nature) in order to try to recover or not to get worse. This is incredibly reckless advice delivered in an unnecessarily smug tone.
632. Janet Harbottle (carer for daughter with severe M.E. for over twenty years)
633. Henry Ward BSc (ME Patient for 3 years)
634. Lurdes López Aduriz (Severa por 10 años)
635. Sara Westrop (ME patient 21 years)
636. Katie Griffiths BSc MRes (Long Covid patient for 3 years with moderate ME)
637. Madeleine Travers (ME patient)
638. Mrs C Gilpin (living with ME for 6 years 2 months)
639. Melissa Wood-Andoh
640. Destiny Toro
641. Jennifer O'Neill MBChB (Moderate ME for 5 years, ME for total of 18 years)
642. Charlie Lockyer
643. Corinne White
644. Anna Bressington BShons, PGCE (now self employed art and jewellery teacher as a result of extreme long covid for 3 years 11 months)
645. Jessica Spencer (ME/CFS Patient for nine years)
646. Laura Anne Mackay BScHlthSci (Hons), (M.E. patient for 21 years)
647. Linda Wigman
648. Gemmi Poliri (Severe ME for a decade)
649. Irene Thorpe (ME for over 3 decades of varying degrees)
650. Emma Matthews (long Covid patient for 2 years with ME like symptoms)
651. Line Robichaud, MBA (moderate ME patient since 2019)
652. Frances Skinner
653. Terry Dixon (M.E. patient for 5 yrs)

655. Thilde Ødegaard (MSc International Business, Management Consultant, just got diagnosed, after viral infection)
656. Amy Ellison
657. Alice Freeman ACA (moderate ME patient for 1 year)
658. Catriona Parfitt BSc (ME patient for 16 years)
659. Phil Latouche (ME patient for 5 years)
660. Heather Montgomery (severe ME patient)
661. James cox
662. Ali Stark
663. Eleanor Rosen (Severe ME patient 47 yrs)
664. Duncan Coombes, BSc, MSc, PhD (Carer for my Severe Wife)
665. Rosie Coombes (Severe M.E. Patient 25 years)
666. Philippa Carbutt (ME Patient)
667. Eleanor Porges MA BA MA. (Severe long covid, EDS and pregnant patient)
668. Miriam Huerster (moderate to severe long covid/ME patient for 4 years)
669. Rebecca Begum
670. Hannah Chong (has had ME for over twenty years)
671. James Connolly
672. Frank Heil (LC and MECFS - 3 years in)
673. Anonymous (ME for 5 years. Now severe)
674. Laura Jones (Long Covid patient for 3 years)
675. Lauren Collins BVSc MRCVS (friend of a person with severe ME)
676. Gillian Spears (Mild ME patient 4 years)
677. Felicity Brienza BA (ME patient for 3 years)
678. Lievina Holtgreffe (3 years Long Covid)
679. Caroline Farmer, M.Sc
680. Nicole Friedland MBBCh
681. Anne Lown
682. Ruth Braham (severe ME sufferer 20 years, totally bed-bound for 10 years, very insulted)
683. Beth Wood MSW
684. Liliom Stanley
685. Mette Boerboom
686. Jessica Gill (ME patient for 18 years)
687. Gemma Mewse (severe LC/ME sufferer for 3 1/2 years)
688. Marie Hélène Labory (PwME for 6 years)
689. Esther Cho
690. Claudine Prud'homme
691. Chris McCabe (partner had a serious chronic post-viral illness)
692. Sarah Fishburn- ME patient
693. Frances Graves (living with ME for 5 yrs.)
694. Victoria Woodhouse FIA
695. Mike Harley
696. Rosie Cox
697. Rosario Fradejad Botran
698. Marilyn Goodger (severe ME patient for 28 years)
699. Wendy MacKenzie
700. Sophie Knox

701. Cheryl Ruzzo (ME Sufferer for 5 years)
702. Nichola McPaul (Severe ME Patient for 12yrs)
703. Craig Robinson MA(Oxon) DPhil FIMA FCA BFP CStat (ME sufferer of 31 years)
704. Carol Parfitt BSc (Parent of severe ME patient)
705. Jenny Billings BScHons MSc (moderate patient pushed into severe after prioritising movement over rest, ill 20 years)
706. Leonie Čović
707. J.E. Barnard (author, advocate, and 33-year ME sufferer who has experienced multiple instances of medical professionals running with one expert's off the cuff remark to pressure me into making myself sicker)
708. Liisa Lugas (severe - profoundly severe ME 21 years)
709. Amy Turner
710. Andrew Whalen (Care Giver)
711. Anusha Stribbling (moderate ME 4 years)
712. Anisha Singh
713. Julia Seip
714. Hanne Haumann (MSc Psychologist/Psychotherapist))
715. David Pinto
716. Lidia Thompson BSc(Hons), PGCE (ME/CFS patient for 35+ years)
717. Shelby spears
718. Kirsty Robinson
719. Suzanne Brooke
720. Diana Montgomery (mother/carer of severe ME patient)
721. Rhys Willetts
722. R D R Willetts
723. Edith Chabot
724. Zia Rahman (LC+ME)
725. Juan Palma Gutierrez (ME Lawyer, Writer, columnist and lecturer at the Seville Bar Association (Spain). Severe ME Patient of 32 years)
726. Steve Churchill MBChB
727. Gabi Lewis (severe ME patient)
728. Dr Nicole Dowley, PhD (ME patient for 15 years, severe for three)
729. Caroline Laflamme (LC/ME for 3 years pushed myself to work and I have to start all over again but worse)
730. Anita Roddam BA Hons PGCE (severe ME patient for 44 years – since 1980)
731. Ana Isabel Lima e Castro Guimarães (Family physician, moderate long covid for almost 3 years)
732. Niamh R MacPhail MA (ME patient for 2 years)
733. Annalena Stache (carer/ support person)
734. Clare Lucas BSc MSc CGEOL (mild-moderate ME for 5 years)
735. Sandra Galvin (moderate-severe ME for 8yrs, started as mild-moderate and deteriorated after “pushing through” and attempting GET
736. Drs. Gertrude de Vries (University degree in medicine, 2001; LongCovid sufferer and mother to 2 (now) adult children with 9 years of ME/CFS, medical teacher)
737. Jane Wess (mother of severe ME patient)
738. Tracy schuler
739. Mahli Jalland
740. Chris Cotter

741. Teresa Pinto MA BA (severe ME patient 3 years, PhD disrupted by illness.
Cannot move my feet without instant severe PEM. This man should be ashamed of himself and he does not represent the severe ME community)
742. Andrew Parfitt
743. Alina Hargrave (I have been helping to care for my son- in - law who has been diagnosed with severe ME)
744. Assunta Süß, MA (ME patient for 2.5 years)
745. Lucy Stokes BSc
746. Shirley Spears
747. Laura Thomas
748. Rose Titchiner (Severe M.E. patient for 17 years)
749. Sandra Galvin (moderate-severe ME for 8yrs, initially mild-moderate, deteriorated after "pushing through" and attempting GET)
750. Menna Messenger
751. Abi Rix (friend of severe ME patients)
752. Aukje Sina Zijlstra
753. Adina Goldin
754. David Spencer (Father of Kara Jane Spener, the tone of the release is shocking)
755. Rachel Monkman (M.E sufferer 16 years)
756. JoJo loebig (severe ME patient 14 years)
757. Esther van de Ruit (ME patent)
758. Hilary Wright (ill for 24 years)
759. Joanne frank (M.E sufferer 20 years no treatment)
760. Menna Messenger (mother of 2 children with ME, 1 of whom is very severe)
761. B Kelly (ME for 3.5 years)
762. Heather Wilhelm (Moderate to Severe ME for 3+ years)
763. Julie Piggott (BA, BHSc, ME patient 3.5 years)
764. Karen Stanbridge
765. Andrea Smith
766. Jennifer Beckers (severe ME patient for 25 years)
767. Julie Morris, MA (ME patient 17 years, former fitness instructor and yoga teacher)
768. Annemarie Stevens (severe me for 15 yrs)
769. Ashley Reilly
770. Dounia Baghdad (Occupational therapist and severe ME patient for 8 months)
771. Kate Warner (BA QTS MA)
772. Alexa King
773. Alexandra Driscoll (moderate to severe 4 years)
774. Kate Reynolds
775. Mr A K Hill (ME sufferer)
776. Sachaa Pattison
777. Joanne Chew
778. Kirsten Boomer
779. Laura Graham
780. Juliet Lockett (ME for 6 years)
781. Linn Halvorsen
782. Ainsleigh Hill, BSc (ME for 3 years)
783. Laura Chatwin MEng (mild/moderate ME 4 years)
784. Shaney Jewell (ME sufferer)

785. Ellen Pickett BASc MBA (ME patient for 28 years)
786. FdSc Jessica Hillwood RVN CertVNECC
787. Ariana Rowberry
788. Henry Gibson
789. Sarah Manners
790. Nancy Cooper (ME patient 5 yrs)
791. Jane Fraser (Severe ME since 2018)
792. Helen Sander BSc (ME patient for 34 years)
793. Sharon Goodwin (ME patient for 27 yrs, Severe for the last 5 years)
794. C. Romyne (moderate ME patient)
795. Emily Thompson
796. Anonymous ME Patient
797. Jill Thompson
798. Kelly Tello
799. Emma Pedley (disability ally and advocate)
800. Lucy King (moderate ME patient for 8 years)
801. Julie Marcoux (Former social worker and ME patient 28 years)
802. Cathy May Brookes BSc (Moderate ME Patient for 2 years)
803. Felicity Cox (ME since 2011, formerly severe)
804. Dr Elke Hausmann
805. Naomi (Severe patient of two years)
806. Ellen Williams (ME sufferer)
807. Janet Hinton-Mann, MFA
808. Sarah Watkins, (MD student)
809. Gill pont
810. Vicky Ball
811. Marco Chao (moderate ME patient)
812. Shannon Hammond (severe ME patient)
813. Ana Hall HBSc (ME for 3 years)
814. Henrik Maeng
815. Catherine Dolan (severe ME)
816. Brian Wernham
817. Doreen Strachan (severe ME patient) Instead of writing snarky editorials, help
Carla Noum and Karen Gordon
818. Debora Haueter
819. Michael Scott (ME CFS patient for ten years)
820. Leanne Spencer BSc (RM) (healthcare professional)
821. Jemma Cottle (Moderate ME patient of 12 years)
822. Dani bell (mild me patient 7 years)
823. Emily Donnelly (undiagnosed ME/CFS patient - 2/3 years in)
824. Sonia simpson 20yr sufferer
825. Maria-louise Williams (Severe/very severe M.E .Tube fed)
826. Jill Tegley
827. Cinnamon Trundle
828. Bridgett Monville
829. Jane Ticehurst
830. Charlotte Anne
831. Alice Wright (ME patient for 15 years)

- 832. Ruth Chalmers (In my 18th year of ME)
- 833. Saaïma A BSc (severe ME patient for over 14 years)
- 834. Ellen Torfs
- 835. Charles walton m.e 31 years
- 836. Jennifer Radomski (moderate ME patient for 8 years)
- 837. Deanna R Boudreau (ME since 1998, severe last 3 years)
- 838. Lauren Rose LLB
- 839. Colleen Lysen
- 840. Joan Murphy former Health Care Aide (moderate ME/ CFS for over 6 years)
- 841. Anna Sheasby Thomas
- 842. Rebecca Goody MBChB, MRCP(UK), FRCR
- 843. Caitlin Corben
- 844. Dr Louise Carter
- 845. Paul Daniels
- 846. Jordanna Freeman
- 847. Katherine Code, BAAC
- 848. Roni Neale (not an ME patient)
- 849. Simone Wilkes, Long Covid Patient 3.5 years
- 850. Paula Hoss
- 851. Jonathan Gutz (ME sufferer 4 years)
- 852. Oonagh McGowan (Long Covid since 2020)
- 853. Chris Thackray MEng
- 854. Lucie Willmott
- 855. Misty Weigold (Moderate/Severe ME patient for 4+ years)
- 856. Jesse Wood
- 857. Caitlyn Neithardt (severe to moderate ME for 15 years)
- 858. Anneke Newman, PhD
- 859. Tracey Harrington (ME patient for 2 years)
- 860. Claire (mild ME, 10+ yrs)
- 861. Dr Jane Hattrick (ME from severe to moderate 30 years)
- 862. Suzanne Short
- 863. Georgia Riley MA
- 864. Emma Louise Flatland, Bachelor of Science (mild/moderate ME patient for 1 year)
- 865. Emma Robbins
- 866. Helen Dowthwaite MA (MusTher), BA (hons) (Long covid 2 years)
- 867. Nicole DeCambra
- 868. Latalia Howell-Deve, BA
- 869. Michaela Rayner (Long Covid/ Severe ME patient 1.5 years)
- 870. Barry Schilling. (Co Chair Stockport ME group charity)
- 871. Sue Saari BSc (ME patient for four years)
- 872. Christine Allon
- 873. Jayne Burbidge
- 874. Maddy (2 years of MD school; severe 10 years)
- 875. Melena Kyriaco - Artist (ME sufferer 31 years self-treated due to lack of medical knowledge & support)
- 876. Jeanette Torr
- 877. Mrs Joanna S Baxter

878. David Baxter
879. Isaac Foulkes
880. Katie Reed
881. Caroline Grégoire, MD (ME patient for 4 years)
882. Hayley Crozier (severe ME for 25 Years)
883. Lisa Edwards
884. Shirlena Monroe (ME for 30 years, severe for past 2, bed bound for the past 10 months)
885. Zoe Hitchen BA (Hons) (Long Covid patient)
886. Rebecca Barrett (Moderate ME of 14 years)
887. Julie Turcotte (Moderate ME patient for 10 years)
888. Joanne Pugh
889. Hayley Scott BSc (HONS) (Severe ME sufferer for over 11 years)
890. Chris Gallagher (Partner of severe ME patient)
891. Hope
892. Lowry Panttaja (severe ME and long COVID patient for 11 months)
893. Mirella Kassowitz (severe ME patient for 1 year, after having LC for 2 years. One hour in the Fitness studio made me totally bedridden for months)
894. Eloise Gardner BHSc, (MOT student; moderate-severe ME patient for 2 years; Aus)
895. Hayley Ashbourne (Moderate ME for six years)
896. Monika Musial MScBMC (ME patient for 13+ years have experienced severe to mild ME and currently moderate)
897. Teresa Graham (mod-severe ME 20 years!)
898. Alina Hargrave (helping to care for my son-in-law with severe ME)
899. Beth
900. Kaschelle Thiessen (ME patient)
901. Alex Allen (person with ME for 20 years)
902. Cheryl Hardy (ME sufferer for 37 years)
903. Emily Kaye
904. Jennifer Caldwell (Moderate & severe ME x 10 yrs)
905. Kaitlyn McBryde (CFS/ME patient since 12 years old (17 years))
906. Amy Arrandale
907. Maria Sale
908. Michael Allen, PhD
909. Caroline Wright
910. Heidi Sauer (ME for 33 years)
911. Sarah Raskin, Ph.D. (ME patient for 18 years)
912. Emily Dupree, PhD, JD, (Founder of Clean Air Club)
913. Sally Anfilogoff
914. Josee Pelletier
915. Ryan Goddard
916. Joanna Fulton (moderate-severe ME)
917. Rachel Hanson (ME patient 36 years)
918. Michelle Bowes (mod ME and fibromyalgia for 9 years)
919. Annette S Engel, MS
920. Kate Barker

921. Emily Johnson (ME/CFS patient for 26 years, medical researcher, medical journalism, medical communications)
922. Wade McCall
923. Jeffery Smith
924. Rebecca Burns BSc (Long Covid for 2.5 years)
925. Jay Stewart (ME patient for 7 years)
926. Cyprin Mason
927. Eva van der Hoek (long covid for 2,5 years)
928. Aimee Evans ME sufferer
929. Emma Houlihan - Moderate ME patient for nearly 6 yrs
930. Alyssa Woodruff (person with ME/CFS)
931. Cristina Rios, MA (Hons), MPhil
932. Chloe Leanne Brookes (Severe ME patient 10 years)
933. T Dooley
934. Morgann McCloskey, ME sufferer of 15 years.
935. Rob Hart, husband of Margherita Hart (very severe ME patient)
936. Rebecca Smith (moderate ME patient for 3 years)
937. Sallie Rediske, MPT (sick since 8; severe for 7 years)
938. Dawn Shimmield (ME 40 years, son badly affected and it killed my mother! 3 generations)
939. Stan Krause
940. Megan Bachtelle-Willars
941. Tara Melanie Irwin, MIR, ME patient of 8 years
942. Shawn Krause. BSc. Mother of adult with severe ME for 6 years.
943. C.fraser, CFS since 2016.
944. Kath G, MA & former semi-professional endurance athlete
945. Emma Liss
946. Sandra Mayor post viral ME patient 2012 & advocate.
947. Mary Beth Johnson mild-severe ME for two years
948. Marusha Taylor, BSc (ME-affected for 24 years)
949. Fiona Renwick
950. Heather Eidbo (severe ME for over 30 years)
951. Natalie Huffman RN
952. Kayla Bruner (ME patient)
953. Emma Carvell, ME patient for 16 years
954. Cassie Goldstein (had M.E for 2 years was severe but now moderate)
955. Alexandria King (ME patient for 2 years)
956. Arun Sekhar
957. Kristine Blackwell (moderate/severe M.E. since 2018; I qualify as a person who lives with this terrible disease and knows how harmful GET has been to me).
958. Sophie Bishton
959. Judith Murphy (ME 10+ years)
960. Kathleen E. Durkin, New York
961. Andrea Frankel (ME/CFS patient for 40 years, formerly licensed Holistic Health Practitioner)
962. Alexandria (Australian with moderate-severe ME)
963. Chris Kemp, ME patient dx'd 33 years ago
964. Emily Locke (severe ME for 10 years)

965. Ashley Espinoza (wellness consultant + blogger + carer)
966. Jaybird Oliver
967. Jane Waters (Carer of ME child now adult)
968. Natasha Derrick
969. Holly Joyce (90% bedbound with ME for 4 years)
970. Amy Kimnings (chronic illness)
971. Rachel Malivindi (ME patient since 2017)
972. Matthew Long (M.E. for 23 years)
973. Lesley Macniven (former ME patient now living with Long Covid)
974. Sally Dixey BEd(Hons) Primary Education, NPQH
975. Loraine Grobler (4 years ME/CFS)
976. Danielle Cogan
977. Rebecca Logan BSc Nursing (moderate/severe Long Covid induced ME patient for 4 years 7 months)
978. Amy Bookham (severe ME)
979. Lori Mandziak (ME/CFS since 2013, long covid 2020)
980. Claire Booth (severe ME patient for 20years and former RGN)
981. Karina Pusey-Mildiner
982. Tessa Keys
983. Madeleine Wallner (Was Severe now moderate/mild M.E)
984. Carla Hill AS, BS, MS (undergraduate research and teaching assistant pursuing Ph.D; when I contracted ME. Now an ME patient for 30 years, severe ME)
985. Enzina Marrari (Researcher, Ally)
986. Michaela Edwards
987. Katie Chapman
988. Jane Birch (ME patient for 5 years)
989. Grace Morris CIM
990. Martin Conway (moderate/severe ME/CFS for the last 5 years)
991. Paul Pettinger MA (ME sufferer of 5 years and former long distance running hobbyist)
992. Jennifer Carter (moderate ME sufferer for 25 years)
993. Arion Xenos
994. Michelle Wainwright-Hicks (struggling with Long Covid/ME for 4 years)
995. Claire Clemons (M.E. patient 15 years)
996. Anna-Karin Ulpe (ME patient 10 years, made severe by advice to exercise)
997. Philippa Taylor (Moderate/severe ME patient for 10+ years)
998. Naomi Appleton (severe ME for 6 years)
999. Philippa Baliman
1000. Rose (mother to daughter who became Severe after GET. Sick now for 17 years)
1001. Julian L'Enfant (partner of someone with ME)
1002. Peter Kemp MA
1003. Yvonne Jackson (LC since 2020, getting worse)
1004. Celia Piquer Poles (severe ME patient post-Covid vaccine (AstraZeneca))
1005. Aurora Dekker (with moderate ME)
1006. Jen Morgan (ME sufferer for over 7 years, never just lying in bed for the sake of it)
1007. Josie Ediss BA (Oxon) - severe ME patient for 2 years
1008. Anonymous H BSc (severe ME since 2021)

1009. Sarah Yeh (moderate to severe 15 years)
1010. Allison Ullrich HBSoc (severe ME since 2021)
1011. Annemarije Schrijber (severe/moderate ME/LC patient for 2 years and 9 months)
1012. Sharon Brockway
1013. Cheri Martin (M.E Patient 20years +)
1014. Ruth Jolly (severe ME sufferer for 4 years)
1015. Sainab Salah MA BA (moderate-severe ME)
1016. Timo Lütke Deckenbrock
1017. Karen Angstadt
1018. Donna Trett MA
1019. Gregory Oakley
1020. Amalie Atkins
1021. Elizabeth Scott MSc PGDip BSc (mild LC w/ME patient for 2.5 years)
1022. Kimberly Fuller (ME for 12yrs, 4yrs severe_
1023. Morag Hill RGN HV (moderately severe ME for 7 years)
1024. Trudie Harkin
1025. Lynn Twohey (ME since a teenager)
1026. Hilde Ringen Johansen (ME-patient for 18 years severe to moderate last 10 years)
1027. Melissa Orobko BSc MSc (mild-moderate ME patient for 3 years)
1028. Jakko van der Pol, PhD
1029. Janaki Silva (severe ME patient for 1 year)
1030. Susie Fletcher (Severe ME)
1031. David Penn, MD
1032. Rachel Keeble (Probable ME for 2.5 years, still awaiting proper diagnosis)
1033. Phoebe Heads (ME patient for nearly two years)
1034. Liz Heads BA(hons) PGCE (parent to teenager with ME for nearly two years)
1035. Bettina Bender (mother of son with ME _
1036. Janessa Culliford (moderate ME patient for 8 years)
1037. Lindsay Davis (friend of someone with ME)
1038. Darcy Sander RN, MN, PMHNP-BC. (ME diagnosed 2005)
1039. Julie Byrne
1040. Simin Ghatineh (PhD, progressive severe ME all my adult life)
1041. Maia Hoey (ME patient 11 years)
1042. CS Ryder, MA (moderate MECFS patient 10 years)
1043. Amy Mooney, MS OTR/L
1044. Cassandra D OFee
1045. Sahar Sadigh Pour
1046. Jessica Mathilde (CFS/ME patient)
1047. Logan Murray (Severe ME for 2 years)
1048. Harriet Elson PhD (ME patient)
1049. Deborah Holcomb Severe ME/CFS (40+ years) (patient/caregiver/advocate)
1050. Rebekah Bailey (Mild-Moderate ME)
1051. Krista Kienapfel
1052. Amina Ali BSc (moderate ME patient 10yrs+)
1053. Ana LoCascio (ME patient for 2.5 years)
1054. Andrea Martell, Bachelor of Journalism with Honours (Severe ME/CFS patient)
1055. Stephanie Forbes (PWME 32 years)

1056. Helen Laird
1057. Allie Trudel (moderate ME patient for a decade)
1058. Pauline Laughton (27 years M.E)
1059. Beatrice Greenfield MSc BA BEd (ME/CFS for 20+ years)
1060. Mary Arroyo (Moderate-Severe patient for 4 years)
1061. Ali Heffetz
1062. Victoria Pires
1063. Anonymous (ME patient 15 years and ex registered nurse)
1064. Alexandria (bedroom-bound with ME in Australia. 17)
1065. Linda Drewry (17 years ME/CFS)
1066. Amanda Silver (moderate ME for 20 years)
1067. Rebecca Gransbury MA BA (ME & Long COVID patient)
1068. Elizabeth Chuter (ME patient for 18 years, severe for 10)
1069. Chris Stubbs
1070. Anonymous (Person with moderate to severe ME, 13 years)
1071. Serieve M. Andrews OSSD ECE (Advocate | Educator; Moderate-Severe ME Sufferer for 9 years; Survivor, Extremely Premature Birth and Brain Injury | Multi-Disabled and Multi-Chronically Ill Individual for life)
1072. Pat Meskell (29 year ME patient)
1073. Anonymous (10 years plus as a patient)
1074. Heather Pearson
1075. Marlon Couture (severe ME patient, 7 years)
1076. Katarina Brandt (very severe ME since 2015)
1077. Emma Denis PGCert Bsc Hons (ME patient 5 Years)
1078. Trish Davis, BSc, (ME 35 years, carer 27 years)
1079. C Rain (moderate/severe ME over 30 years)
1080. Vanessa Waterhouse
1081. Barbara Robinson BA (Hons) Cert Ed, Cert Cartography (Carer for 2 with ME for 30 odd years; Suffolk Youth & Parent Support Group., Suffolk and NEEssex ICB Service Development Working Group)
1082. Sarah McInnes, Physiotherapist (ME patient for 12 years, currently moderate-severe)
1083. Lisa Wynne (Mod/Severe patient)
1084. Tanya Donaldson
1085. Jessica Diamond
1086. Alexandra Brooks (moderate M.E. patient for 6 years)
1087. Laura Barker BSc (A&E RN; got covid at work and unable to live since 2020-2021)
1088. David Cox MA(Cantab) (carer for wife with M.E.)
1089. Tamara Epps (M.E patient for 21 years)
1090. Sophie Michelle Innocent (girlfriend and carer of ME patient for 7 years)
1091. Natalia Tkaczyk
1092. Rowe Wylde (moderate ME and caregiver to a severe ME patient)
1093. David Metcalf (father of woman with ME)
1094. Helen Myers
1095. Stephen Roberts (pw ME)

- The original column by Neil Reily was published in the ME associations magazine and is available to read here: <https://bit.ly/MEAcolumn>
 - He also authored [this column in 2019](#)
 - If you have any queries, would like to edit or remove your name please email Alexis: alexis.cfsme@gmail.com but bear in mind I have severe ME and a response may be delayed.
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