

ME SUPPORT NORTHERN IRELAND

# VOICES FROM THE SHADOWS, PARLIAMENT BUILDINGS, BELFAST.

ME PATIENTS HAVE THEIR SAY

MONDAY 18 FEBRUARY 2013

## Voices From The Shadows

### Voices

*Voices from the Shadows is a heart-rending documentary, which describes psychiatric mismanagement and abuse of vulnerable ME patients in the UK. The Long Gallery was completely silent for the one-hour duration of the film. MLAs stayed for the entire viewing, and a number of patients were in tears much of the time. There was a feeling that this breakthrough documentary should be shown far and wide, among the patient constituency and beyond it.*

## ✕ Long Gallery, Stormont. ✕

*The Long Gallery at Stormont is Northern Ireland's showcase venue for major political events. Two Presidents of the United States greeted politicians in this room, during preliminaries of the Good Friday Agreement.*

### ME PATIENTS MADE WELCOME

In the UK, ME patients are routinely excluded and

ignored during consultations on how their healthcare should be shaped.

Instead of being given what they need and want, they receive only what it profits some NHS practitioners to offer them. But in

Belfast Sue Ramsey, Chair of the Assembly's Health Committee, has a philosophy that patients

should have free access to their politicians. So on 18 February



she arranged for Northern Ireland ME patients to have their say in the seat of Government at Stormont.

### WHAT ME PATIENTS WANTED

“Don’t import psychiatric mismanagement of ME into Northern Ireland”, we asked.



### WHAT ME PATIENTS GOT

Mr. Jim Wells, the Health Minister-elect told us: “We MLAs are the converted. ME is NOT a psychiatric disorder”.



## WELCOME FROM SUE RAMSEY & ANTOINETTE CHRISTIE



Sue Ramsey is the no-nonsense Chair of the Northern Ireland Assembly's Health Committee. Welcoming ME patients and their families, she said voters oughtn't to be afraid of their politicians, and should have free access to them.

Antoinette Christie, the go-getting Chair of ME Support Northern Ireland, welcomed guests. She started proceedings with an offer of coffee, tea, sandwiches and music, all within the capacious confines of the Long Gallery.



## SUN, COFFEE, MUSIC & CHAT.

### **Music:**

Everybody Hurts  
The Rose  
The Calling  
Timshell  
No Cover Up  
Sophia  
Eye of the Tiger



Beccy Henderson and Rosy Barry provided the music. Health Committee Chair Sue Ramsey chatting with Jeanette Marley & Antoinette Christie of MESNI, and Martina Marks & Joan McParland



of Newry & Mourne ME/FM Support Group. Jean & Mark Stapleton (r) are from Bangor. Their daughter Hazel hosts the "Eagles Wings" website at [www.oneagleswings.me.uk](http://www.oneagleswings.me.uk)





## MRC “PACE” TRIAL FAILURE

Horace Reid updated the audience on the ongoing failure by the local Trusts and Health and Social Care Board to implement best practice care for ME patients in Northern Ireland. He also reported that treatments in the £5m MRC-funded PACE trial had failed to deliver promised reductions in uptake of Social Security benefits among ME patients. Nor had any patients been able to return to employment afterwards. “The PACE trial bubble is now burst”, as he put it. He introduced patient and professional participants in “Voices”, and warned the audience the documentary would be harrowing to watch.



## HARROWING FILM

There was complete silence in the Long Gallery for the one-hour duration of this disturbing documentary. Case after case was presented where severely ill ME patients had been abused and neglected at the hands of NHS professionals - most of them psychiatrists. The ME community are well aware of the dreadful treatment accorded to Lynn Gilderdale and her mother Kaye, and to Sophia

Mirza and her mother Criona. But now details of these cases were coming to the attention of elected representatives in a Parliamentary assembly. During the film a few highly-principled doctors spoke out against prevailing psychiatric mismanagement of ME patients in the UK - Professor Leonard Jason from Chicago, and Dr. Nigel Speight from Durham, both of them experts in ME care. Some patients hadn't seen this film before, and were in tears throughout the showing.



Jim Wells is Deputy Chair of the Health Committee, and Health Minister-elect. He is a steady friend to ME patients in Northern Ireland. He deplored antiquated attitudes to the illness held by some

doctors. He congratulated the committees of MESNI and Newry & Mourne ME/FM Support for their efforts to improve ME services within the NHS, and promised his continuing support.







Catherine Burrell, David Christie, Roy Beggs MLA, and Leah Bell. Roy Beggs didn't know much about ME, but he does now! He reckons adoption of the Canadian Criteria is the way forward.



Catherine Burrell, and Keith & Uli Speers in the sunlit Long Gallery. Uli is researching counselling support for relatives of ME patients, at the University of Ulster.



Alderman William Leathem is Mayor of Lisburn City Council. He owned three commercial enterprises, but had to sell them when he contracted ME. He uses pacing to manage his Council duties.

## MADE TO FEEL AT HOME

Like doctors, politicians have surgeries. But unlike doctors, our local politicians don't treat ME patients as pariahs.

When they were well and in employment, ME folk paid their taxes like everyone else. But once they became ill, the NHS began treating them like lepers, denying them competent care, stigmatising them, and misdiagnosing & abusing many.

It wasn't like that at Stormont on 18th February. Politicians threw open their doors and welcomed ME patients in large numbers to the heart of government. For once in their lives ME folk were given respect and treated normally, just like all other citizens.

ME patients were made to feel at home by MLAs of all parties. - Which was as it should be, and a very welcome change.



Joan McParland from the Newry & Mourne ME/FM support group brought a sizeable delegation to Stormont to lobby the MLAs.



## PREMIER POLITICAL VENUE

### MLAs Present Included:

Roy Beggs  
Jo-Ann Dobson  
Sam Gardiner  
Danny Kennedy  
Kieran McCarthy  
Rosaleen McCorley  
Sue Ramsey  
Jim Wells  
A number agreed to  
join the planned All-  
Party Group on ME.

## ME SUICIDES

The Long Gallery is Northern Ireland's premier political venue, and MLAs made it available for ME patients to have their say. Charity workers in this sector are becoming increasingly aware that suicide is a major feature with ME patients, particularly now access to Social Security benefits is

becoming more difficult. A number of representatives from suicide prevention charities were present, including members of Feile Joe in Co. Armagh. One patient told the audience of her recent unsuccessful suicide attempt. "I don't actually want to die. But I can't go on living with this awful disease if I don't get proper support", she said.



## BUREAUCRATIC PARALYSIS

There are 7000 ME patients in Northern Ireland, and according to NICE they are just as ill as those with "multiple sclerosis, SLE, rheumatoid arthritis, & congestive heart failure." But the NHS here continues to ignore, ostracise and neglect this very large group of vulnerable patients.

In 2008 the Health and Social Care Board and the Health Trusts were instructed to implement best practice guidelines for the care of ME. Five years later they have failed to implement more than a few token items of these recommendations.

On 18th February the politicians were doing their job, by giving a voice to ME patients. It is high time bureaucrats in the NHS did their jobs also.



Feile Joe, Suicide  
Prevention, Co. Armagh

