

The Inauguration of the NGO Committee for Rare Diseases - Statement from Baroness Campbell, Independent Member of the UK House of Lords

I'm sorry I cannot be with you today but my days of hopping on an aeroplane across 'the pond' are sadly behind me. I do however, have very happy memories of my trip to New York 25 years ago when I attended the first international conference for disabled women. Not only did I meet the most inspiring women, liberating disabled people in countries where disability was considered the worst taboo, but I also experienced a city where disabled people had access to buses and public buildings, long before the UK. I felt a freedom in New York that blew me away and inspired me to go back and fight harder for inclusion in the UK. So yes, New York is the perfect city to inaugurate the Committee for Rare Diseases!

My own hopes for the Committee is that it will work in true partnership with disabled people who have a rare disease. I hope it will be a shared enterprise, looking for new ways to support those who are living with a rare disease, at the same time as researching how to eradicate or prevent, the worst effects of a rare condition.

In England disabled people have a very important saying, "nothing about us, without us". My request from the UK is please put this at the heart of the Committee's statement of intent.

Disabled people are the experts of their own circumstances. For hundreds of years our voice was silent, as others believed they knew what was in our best interests. We were not included in society. Instead billions of pounds were spent on keeping us segregated and silent. Out of sight, out of mind. Society once poorer for it. Like so many disadvantaged groups, disabled people had to find a way to organise into a small army to fight for our liberation and civil rights. Many today, are now 'out and proud' around the world. We demand to be treated as equal citizens with a place at the table. That's the mark of a progressive society.

As someone who has survived a diagnosis of Spinal Muscular Atrophy Type 1, which was considered a rare disease in 1959, I have learned that cure is not my central desire in life. I like who I am, including my disease, not despite it. I wouldn't have it any other way. However, I don't like the chest infections and I would like a little more strength to continue debating and talking. Research could help find ways to offset the worst effects of the disease. So I'm hoping the Committee will have a balanced approach to its work. Looking at new ways to support those living with rare diseases, balanced with research on future prevention.



The Global Gathering for Rare Diseases

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In my first 20 years I hid in the shadows, ashamed of who I thought I was. The following 35 years, I danced in the sunshine. What made the difference? The answer was simple – I wasn't the problem but society was. I couldn't change my DNA, but with other like-minded disabled people, we could change society, with all its disabling barriers. I found my voice and my self-respect. People were forced to listen. They are still listening – now in the heart of government. The weakest can be the strongest, whatever their rare disease. Let us celebrate that diversity by working together for a more mutually supportive world.

Have a wonderful inauguration, I am with you in spirit.