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# A short history of the World Muscle Society

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As the World Muscle Society celebrates its 10th birthday, I thought it opportune to reflect on some of its early developmental milestones.

## 1. Flirtation

In the early months of 1995 Luciano Merlini and I flirted with the idea of forming a new muscle society. There was a general feeling within the neuromuscular fraternity that the 4-yearly muscle congresses organised by the World Federation of Neurology, were too large and too expensive. In addition the whole field was advancing at such a rapid rate that the 4-year interval between meetings was much too long. There thus seemed to be an inherent need for a new multidisciplinary society to meet on a more frequent basis and to direct its objectives more to the active research community rather than the established icons, who were recycled from one meeting to the next in the WFN congresses. We were still at a stage of very preliminary and informal discussions when things took a leap ahead for a totally unpredictable reason.

## 2. Consummation

In February 1995 I had to change at short notice the travel arrangements for a preplanned academic and clinical visit to Luciano's unit in Bologna, so instead of buying a regular airline ticket at a preposterous price, I bought two back to back apex tickets, and left the two return halves straddling the first weekend in March. As the time approached, I thought might actually utilise them for a free trip and arrange a meeting together with Giovanni Nigro in Bologna on the Monday, 6th March. We had a very productive debate and the recently established

Mediterranean Society of Myology, which brought together the well-established regional conference activities of Giovanni Nigro in Naples and George Serratrice in Marseilles, provided a good model for the establishment of a more universal society. After discussing various possible names we opted for World Muscle Society, as most clearly defining the nature of the society. The main aims of the new society would be to provide a multidisciplinary forum for advances in neuromuscular disorders that was not met by either the four-yearly international congress, or by the national, more regional meetings, or by the workshops of the European Neuromuscular Centre (ENMC) which by their very nature were confined to a single disease or topic and limited to a small cohort of people. We envisaged a congress that could perhaps provide on a larger scale a workshop type of format.

We decided the next important step would be to convene a meeting of Founder Members of the new society, who would be representative of the multidisciplinary nature of the field and also the geographical spread. I offered to host a meeting of the founder members in London and we set the date for Sunday 4th June. We also started drawing up a list of potential founder members of key researchers in the field, covering four broad interdisciplinary categories of clinical, molecular and genetic, pathology and experimental, and cell biology and biochemical.

We then adjourned to one of the Bologna gourmet restaurants to celebrate the conception of the new society and to toast its health. (Fig. 1).

## 3. Birth

After a short gestation of only three months, the society was born in London on Sunday 4th June 1995. In the ensuing weeks after the Bologna meeting I sent a letter to some 60 potential foundation members asking two questions 'do you think there is a need a for a new international muscle society to arrange more frequent interdisciplinary meetings; and would you be able to attend a foundation

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Fig. 1. Giovanni Nigro, Victor Dubowitz and Luciano Merlini at celebratory dinner after conception of the World Muscle Society in Bologna, Monday 6th March 1995.

meeting of the new society in London on Sunday 4th June, 1995?’

All but two responded positively to the need for a new society, and 15 agreed to attend the foundation meeting in London, including two from Japan, one from the USA, one from South Africa, and the remainder from various European countries, with three local people from the UK. So I finalised arrangements to hold the meeting at the CIBA Foundation (now Novartis centre) in central London, which also had residential accommodation for out of town participants.

The foundation members attending were Corrado Angelini [Italy], Victor Dubowitz [UK], Laszlo Dux [Hungary], Lars Edstrom [Sweden], Robert Griggs [USA], Hyam Isaacs [South Africa], Jean-Claude Kaplan [France], Luciano Merlini [Italy], Giovanni Nigro [Italy], Eijiro Ozawa [Japan], Georges Serratrice [France], Hideo Sugita



Fig. 2. Foundation meeting of World Muscle Society, at CIBA [now Novartis] in London, Sunday 4th June 1995. From left back row Dux, Angelini, Griggs, Vrbova, Swash, Serratrice, Nigro, Kaplan, Ozawa, Merlini; front row Isaacs, Edstrom, Sugita, Tome, Dubowitz.

[Japan], Michael Swash [UK], Fernando Tomé [France], and Greta Vrbova [UK] (Fig. 2).

Limitation of time helps to concentrate the mind. By 6 pm we had completed our business, agreed the name for the Society, World Muscle Society, as well as its credo ‘An international multidisciplinary society for the promotion and dissemination of knowledge in the neuromuscular field for the benefit of patients’ and also a charter. An executive board was elected comprising a president (Dubowitz), secretary (Merlini) and treasurer (Nigro) plus eight additional members, Kiichi Arahata [Japan], Laszlo Dux [Hungary], Robert Griggs [USA], Eric Hoffman [USA], Francesco Muntoni [Sardinia], George Serratrice [France], Fernando Tomé [France] and Thomas Voit [Germany]. The executive board agreed to adopt *Neuromuscular Disorders* as its official journal and accepted my offer to host the first annual congress of the Society in London in September 1996. It also elected an international advisory board of some 68 clinical and basic scientists worldwide, who had expressed interest in the formation of the society.

We then set off for a celebratory dinner at Chez Gerard, a French restaurant nearby in Charlotte Street. It was reassuring that our French colleagues were reasonably happy with the quality of the food as well as the wine. One of our foundation members who had a passion for whiskey and a relative aversion for wine, was able to achieve level pegging with the wine drinkers on a glass for glass basis, and considerably enhanced our bill for the evening.

#### 4. First steps

Achieving independent ambulation is an important milestone in the motor development of an infant, and so it was for WMS. My offer to host the first conference within a year of the society’s foundation proved to be a pretty tall order, and I soon realised I may have bitten off more than I could chew. All we had was a nascent society, with no members yet, no budget, no venue and no guidelines for the congress. So we had to ensure that the congress would be self-supporting from the income from registration, which had to be at a reasonable level to be affordable for active young researchers. We had an ad hoc program committee comprising Luciano Merlini, Fernando Tomé and myself, and we also had considerable input from Reinhardt Rudel, who had convened a most successful international congress for WFN in Munich in 1990. I also had considerable input locally from my colleagues Francesco Muntoni and Caroline Sewry.

I initially approach some congress organising agencies but these were prohibitively expensive, so we were soon in a potential cul de sac of going it alone. A possible solution presented itself, when I found out that Elsevier had a department that organised conferences in relation to some



Fig. 3. Organisers of the first 10 annual congresses of WMS, left column from top down, Giovanni Nigro Naples 1998; Faycal Hentati and Mongi Ben Hamida Tunis 1997; Haluk Topaloglu and Beril Talim, Antalya 1999; John Rodda and Gail Scher, Kruger National Park 2000; right column from top, Kevin Flanigan Snowbird 2001; Laszlo Dux, Szeged 2003 and Nicolette Notermans, Rotterdam 2002; Anders Oldfors, Goteborg 2004; Mariz Vainzof, Iguassu Falls 2005. Not pictured, Victor Dubowitz, London 1996.

of its journals and their associated societies, so I pursued this option and had a lot of help from Penny Moon, the person in charge of this section at the Oxford based wing of Elsevier, particularly in relation to choice of venue, which we visited together. We settled for the Commonwealth Institute, which had good facilities for a meeting of around 200–300 participants and a good ambience, and was reasonably priced. It was also fortuitous that the Association of British Neurologists, of which I was a

member, would be having their annual meeting there, which I attended in order to get a first hand perspective of the venue. We were also keen on a banquet as a special and important component of our congress in order to promote some social integration of our new society. I accordingly paid my £40 for the ABN dinner held at the Science museum, a potentially interesting venue for us as well. The venue and the dinner were fine; the only problem was that only about 40 people attended, defeating in many ways

the objective of an official dinner. The vast majority of neurologists ended up at competing free dinners hosted by pharmaceutical companies.

That was an important experience for me as I decided there and then that all our participants would attend our own dinner, and the cost would be inclusive within the registration.

Another firm objective we had from the beginning was that the conference would be directed at the active young researchers. We thus worked out a novel approach based on the concept of the ENMC workshops, of selecting three major topics that were currently active in the muscle field and devoting one of the three days to each topic, with a small number of invited keynote speakers on each topic to summarise the current status of that topic from a clinical and research perspective. The rest of the day was devoted to contributed papers on the selected topics, partly by oral presentation but mainly by poster, all of which would be fully discussed with two co-chairmen. We also invited contributions across the neuromuscular field, which would be presented by poster only, with selective discussion as time allowed.

This core structure has remained the pattern in all our ensuing conferences to date, with a lot of fine-tuning on the way. It proved to be especially popular with the young researchers, who felt they were given good exposure of their research as the posters remained up throughout the meeting and the individual discussion sessions were organised with the same vigour, as were the oral presentations. We also had a very convivial and successful banquet on board a boat sailing up the Thames, attended by all participants and their partners.

There were innumerable hiccoughs on the way, which don't bear repeating apart from the important lessons we learnt from them. Amongst the major hurdles we had to contend with was that Elsevier decided to move the management of our journal from Oxford to Amsterdam, with almost instant effect, which meant a whole change of scene and control and starting afresh with a new publishing editor, based in Amsterdam and not in Oxford. To add further fat to the fire, the production of the journal was now moved to a totally new team, with no experience of medical publishing, in Elsevier production centre in Shannon, Ireland. In no time flat the journal, which had been running a month ahead of schedule was three months behind. The final straw came as we were starting to get the abstracts coming in, when I had a cold call from a very pleasant but completely unknown American lady in Cardiff, who told me that she did part time editorial work for Elsevier and had just been retained to oversee the publication of the abstracts for our conference. Could she arrange to meet me in London to get some information on what the conference was all about? I was almost apoplectic. No surprise then when the proofs of the abstracts eventually arrived that they were in a state of total disarray and I spent countless hours copy editing

them myself to at least get them into a reasonably acceptable state.

As they say in the theatre, it will all be all right on the night! We did finally make it, by a hair's breadth. The congress duly opened, had a good attendance, and the Journal supplement of abstracts duly arrived, on the opening morning of the congress! The important thing in life is always to learn from and capitalise on one's experiences. Having ended up doing most of the work for the congress ourselves, we decided in future years just to organise our conferences ourselves, and control our own finances. So we set up a core program committee for the society, comprising the president, the secretary and one additional member of the executive board, who would work closely with a local convenor, who in turn would organise a local team of colleagues to assist with the organisation, and also as required a professional organisation to handle some aspects of the registration and facilities.

## 5. Growth and development

When the society was founded in 1995 we optimistically set ourselves a goal for going from zero membership to 500 by the end of the millennium, and we did actually achieve that mark in 2000. With each succeeding congress we have acquired new members but each year there have also been a proportion who have not renewed their subscription. For the past few years the membership has had a steady state of around 600, which may well be an optimal level for having a strong enough core of members to ensure a consistent attendance at the annual congresses, and at the same time to not exceed beyond a manageable number of participants at the congress to maintain our workshop-like format.

Whilst the basic tenets of the society have not changed at all over the years, we have had to adapt to circumstances and put forward to our annual assembly of members some changes in the constitution.

The original charter provided a two-year term for the executive board and an option of standing again only once for re-election. We faced a crisis when we got to the 4th year of the almost total disappearance of our foundation executive board and having to start again with a new executive board, which would again choose its president, secretary and treasurer. So we initially got approval from the assembly for an extension of the term of office to 3 years, which proved more satisfactory, and an amendment that all members of the board could stand again at successive elections. This has indeed provided the stability as well as a turnover in the board.

The conferences have gone from strength to strength each year. We have looked for venues that were interesting in themselves but more importantly off the main stream of major congresses, so that we could negotiate reasonably



Fig. 4. The president on his toes (or knees). First steps in belly dancing, Antalya 1999; Shangaan chief, Kruger Park 2000; “Happy Birthday Mr President” (70th), Snowbird 2001; Old Master, Rotterdam 2002.

priced packages for our young and active participants, who did not have access to lavish travel funds. All applications are discussed by the executive board; following presentation by the local convenor. The core program committee together with the local organiser have met up each year at the local venue, some 4 months ahead of the congress, for an intensive weekend finalising the whole program and getting it ready for publication in the concurrent issue of *Neuromuscular Disorders*. After Luciano did not stand for

re-election as secretary to the executive board in 2001, he was succeeded as secretary by Haluk Topaloğlu. When Fernando Tomé did not stand for reelection, we co-opted him onto the program committee as an *ex officio* member, in addition to appointing Thomas Voit from the executive board as his successor.

The following is a summary of the venue, local organiser, and the selected topics of the first 10 congresses to date (Fig. 3):

**WMS 1** 25–27 September 1996—London.  
Victor Dubowitz  
Topics: Congenital Muscular Dystrophy; Spinal Muscular Atrophy; Ion Channel Disorders

**WMS 2** 16–18 October 1997—Tunis.  
Fayçal Hentati  
Topics: Congenital myopathies; Distal myopathies; Hereditary neuropathies and ataxias

**WMS 3** 29–30 May 1998—Naples.  
Giovanni Nigro  
Topics: Cardiomyopathies; Therapeutic possibilities in neuromuscular disorders

**WMS 4** 14–16 October 1999—Antalya.  
Haluk Topaloglu; Beril Talim  
Topics: Autoimmune disorders of muscle and nerve and advanced in immunotherapy; Sarcoglycanopathies and limb girdle muscular syndromes; Mitochondrial disorders of muscle and nerve

**WMS 5** 25–29 June 2000—Kruger Park, South Africa.  
John Rodda; Gail Scher  
Topics: Muscle development and the congenital myopathies; Advances in the muscular dystrophies, including therapy; Muscle disorders in animals; spontaneous and induced

**WMS 6** 5–8 September 2001—Snowbird Resort, Salt Lake City.  
Kevin Flanigan  
Topics: Update on facioscapulohumeral and other dominant muscular dystrophies; Update on spinal muscular atrophies and motor neuropathies; Therapy and management in neuromuscular disorders

**WMS 7** 2–5 October 2002—Rotterdam.  
Nicolette Notermans  
Topics: New insights into the muscular dystrophies; Immune mediated diseases of nerve, neuromuscular junction and muscle; Therapeutic highlights in neuromuscular disorders

**WMS 8** 3–6 September 2003—Szeged.  
László Dux; Luca Mendler  
Topics: New trends in the congenital myopathies; Signalling in developing and diseased muscle; New horizons in the treatment to neuromuscular diseases

**WMS 9** 1–4 September 2004—Goteborg.  
Anders Oldfors  
Topics: Sarcomeric and cytoskeletal proteins and their diseases; Clinical and genetic aspects of nerve and muscle disorders with nucleotide repeat expansion; Progress in therapy of neuromuscular disorders

**WMS 10** 1–4 September 2005—Foz do Iguaçu.  
Mariz Vainzof  
Topics: Advances in limb-girdle muscular dystrophies; New developments across the neuromuscular field; New horizons in therapy of neuromuscular disorders

All our conferences have provided a good combination of academia and social activity and in the Snowbird congress I dubbed our society the Triple E Society [Education, Enjoyment, Excitement] to reflect the three important components of our congresses. Every successive organiser has striven to achieve all three in good measure. In addition some organisers have provided some extra excitement for the president (Fig. 4).

Every congress to date has also more than fulfilled the credo of the society, which our founding fathers spelled out at our very first foundation meeting in June 1995, ‘An international multidisciplinary scientific society dedicated to the advancement and dissemination of knowledge in the neuromuscular field for the benefit of patients.’

I feel confident in predicting a healthy adolescence and a bright future for our energetic and thriving society.

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