

**Spinal Cord Leaders Council  
Monthly Teleconference Meeting**

**Thursday, February 21, 2008  
3PM**

**MINUTES**

**Attendees:**

Woodbury, Deb, RN – Spaulding Rehabilitation Hospital  
Weisman, James – United Spinal Association  
Tobin, Paul J. – United Spinal Association  
Hudson, Lesley – American Spinal Injury Association  
Polonsky, Dana – Craig Hospital  
Roth, Marcie – National Spinal Cord Injury Association  
Prokop, Susan – Paralyzed Veterans of America  
Cahill, Ida – Sam Schmidt Paralysis Foundation  
Hathaway, Peggy – United Spinal Association  
Kloter, Karen – Commission on Accreditation of Rehab Hospitals  
Gray, Phyllis – Kennedy-Kreiger Institute  
Maher, Pat – National Spinal Cord Injury Association  
Morris, Andrew – United Spinal Association  
Dyson-Hudson, Trevor, MD – Kessler Medical Rehab Research & Education  
Hathaway, Peggy – United Spinal Association

**1. Call to Order and Roll Call**

The meeting was called to order at 3:05 by Chair Paul J. Tobin.

**2. Welcome Remarks**

Mr. Tobin thanked everyone for joining the call and welcomed 2 new participants: Deb Woodbury, RN, Spaulding Rehabilitation Hospital, and Trevor Dyson-Hudson, MD, Kessler Medical Rehab Research & Education. Mr. Tobin reiterated the Council's purpose: to collaborate on policy topics and pool resources on any issues of interest and concern to the spinal cord injury community.

**3. Agenda**

The proposed agenda was unanimously adopted.

**4. Minutes of 1/17/08**

The minutes were accepted as submitted.

**5. Committee Reports**

- a. Candidate Platforms** – Ms. Roth reported that a draft questionnaire had been circulated to the members, and that no feedback was received; she

hopes responses will be forthcoming so the draft document can be finalized. Ms. Roth stated that in the meantime a meeting had been held with the democratic national committee chair, and that we will also be contacting the republican counterpart. The intention is to send the questionnaire out to every member of congress, as well as to the candidates.

**Ohio Disability Forum:** A forum similar to the one held in NH in November is being considered in Ohio on July 26<sup>th</sup>. The NH forum, co-sponsored by 20 national organizations and some local groups, was extremely well attended. Candidates sent high-level representatives, if they could not attend in person, to discuss the candidate's disability agenda. The Ohio forum would be hosted by the Ohio Coalition of Citizens with Disabilities, and every organization on the Council can be a co-sponsor if they so choose. We need to get candidates to think of people with disabilities as an important voting bloc.

- b. DME and “In the Home”** – Mr. Morris reported he has talked to Henry Claypool, ITEM Coalition, about collaborative initiatives. A meeting will be arranged between Peter Thomas and the rest of the committee to strategize between groups and see what is going on. They would like to reach out to and determine the cost of private care. They hope to arrange Hill visits in the next month or so. Mr. Morris will be drafting a letter that Council members can sign on to, which will be used in conjunction with congressional visits. Mr. Tobin reiterated it was the purpose of the Council to sign on to issues we are contacting legislators about, so that positions are representative of the largest group possible.
- c. Christopher and Dana Reeve Paralysis Act** – Mr. Tobin reported that his efforts to contact Foundation committee members had been unsuccessful. It was the consensus of the group that if we have a committee that is not working, there is a need to reappoint, since the committee was formed to perform a function that the Council considers important: influencing as a group passage of the Act, and determining our involvement once it is passed. Ms. Prokop was asked and agreed to chair the Christopher and Dana Reeve Paralysis Act committee. Mr. Tobin will be contacting some of the original committee members to confirm their willingness to serve.

**Tentative Committee composition:** Susan Prokop (Chair), Marcie Roth, Marc Johnson, Sunny Vance-Lauritzen, Andrew Morris, Phyllis Gray, Gary Ulincy.

## 6. Other Business

- a. The incident of a FL deputy sheriff dumping a quadriplegic man out of his wheelchair because he would not stand up was discussed. Everyone was horrified and wondered what could be done to prevent mistreatment of people with disabilities by law enforcement personnel. Corrective action against the 4 sheriffs involved has been taken; otherwise, the Council would send a letter demanding termination of employment. Mr. Weisman stated that United Spinal Association does sensitivity and etiquette trainings for police academies; we emphasize that mistakes, when dealing with people with disabilities, are always painful and can be life-threatening. Mr. Tobin stated that since this incident is in the media, organizations should use it as an opportunity to raise awareness about spinal cord injury and about how to handle this type of situation.

Ms. Roth and Mr. Tobin will explore ways to keep these issues on the table with law enforcement agencies and organizations, and report back. It was pointed out that the National Association of Police Organizations sends out training materials and should be approached. Mr. Weisman recounted the case of an SCI inmate who is doing time in an Ohio prison (allegedly for a wrongful conviction), who is ill and in peril of losing his life before parole (in 2 years), due to lack of adequate day-to-day healthcare. It was noted that there is a case filed with the Fourth District Circuit concerning prisoners' rights. It might be interesting to investigate how far to the front-end it extends.

- b. **Social Security – Ways and Means Committee:** It was reported at the last meeting that Mr. Terence J. Moakley gave testimony against proposed rules concerning appeals for denials of social security disability. We have since been informed that the commissioner is withdrawing the “controversial stuff.” We will need to find out and evaluate exactly what this means.

Ms. Roth commented that in the waning weeks of this administration there seems to be a lot of proposed rule-making going on. It was agreed that everyone needs to be hyper-vigilant to make sure nothing slips under the radar. Professional associations in particular might hear things through the grapevine. Everyone needs to keep eyes and ears open. We will need to review DOJ's modifications to the ADA Restoration Act, as well as the rebuttal from the National Council of People with Disabilities and post links to our website – [www.spinalcordleaders.org](http://www.spinalcordleaders.org)

7. **Adjournment:** The meeting adjourned at 3:45 PM.

**Next Meeting:** Thursday, February 21, 3:00 PM Eastern Time.

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