

**Spinal Cord Leaders Council
Monthly Teleconference Meeting**

**Thursday, December 20, 2007
3PM**

MINUTES

Attendees:

Morgan, Bruce, Christopher and Dana Reeve Foundation
Maher, Pat, National Spinal Cord Injury Association
Gray, Phyllis, Kennedy-Kreiger Institute
Larson, Eric, National Spinal Cord Injury Association
Polonsky, Dana, Craig Hospital
Kloter, Karen, Commission on Accreditation of Rehab Hospitals
Johnson, Mark, Shepherd Center
Prokop, Susan, Paralyzed Veterans of America
Maher, Pat, National Spinal Cord Injury Association
Cahill, Ida, Sam Schmidt Paralysis Foundation
Morris, Andrew, United Spinal Association
Hathaway, Peggy, United Spinal Association
Tobin, Paul J., United Spinal Association
Weisman, James, 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

Due to United Spinal's impending office move during the Holidays, emails submitted between now and the January 2nd might be delayed in transmission. Members were asked to re-submit emails after the first of the year if they experienced prolonged delays in getting replies.

3. Agenda

The agenda was unanimously adopted as submitted.

4. Minutes of 11/15/07

The minutes were accepted as submitted on a motion duly made and seconded and passed unanimously.

5. Introduction of New Members

Mr. Tobin reported the following new members: American Association of Spinal Cord Injury Nurses (AASCIN), American Association of Spinal Cord Injury Psychologists and

Social Workers (AASCIPSW), American Paraplegia Society (APS), and American Spinal Injury Association (ASIA). The latter will be represented by Executive Director Leslie Hudson. The new members are a welcome addition to the Council; they will bring clinical perspectives on some of the issues, which will carry over to public policy. Total Council membership to date is 16 voting organizations. We are still looking for new members, though we are nearing bylaw-mandated quota of 21 organizations.

6. Committee Reports

Durable Medical Equipment and “In the Home” – The committee met on November 30th. The committee is working on strategy for making Hill visits. The committee will strive to maximize its work and maintain its own identity, while continuing relationship with other coalitions. It is the Council’s stand that equipment must be customized to each individual’s home care situation. There is a need to develop sound-bites around DME to blog in wherever appropriate and share with congressional leadership. Messrs. Tobin and Larson will assist, as part of their function on the communications committee.

Christopher and Dana Reeve Paralysis Act – The bill, which is intended to advance collaborative research in paralysis and improve quality of life for people living with paralysis and mobility impairments, was passed by the U.S. House of Representatives on October 15th. In November, the Senate tried to pass its version of the bill by unanimous consent, but a Republican Senator objected and asked for an authorization offset (funding mechanism) for the bill. A non-appropriation funding provision was put together and offered for consideration. However, the funding mechanism was rejected by the bill’s sponsor on the grounds that an authorization bill does not require funding. The bill’s sponsor is committed to working with Senate leadership to pass the legislation in 2008 and to subsequently fund the programs through annual appropriations. If the Senate bill passes in its current form, it will then have to be reconciled with the House passed version of the bill.

The committee was asked to communicate to Senator Harkin’s staff that the bill has the backing of the Council, which represents 16 distinct organizations, and to provide them with a list of organizations.

Candidate Healthcare Platforms – Draft of questions need to be shared among committee members. The committee will meet in early January to develop a draft questionnaire that will be shared with the Council.

Communications Committee – A generic press release about the Council was sent to committee members, to adapt and send to health committee staffers and other contacts. The committee will be putting together talking points around DME issues. Other projects for the committee: getting the website, www.spinalcordleaders.org, up and running with press releases and policy

positions; developing a blog that members from the Council can add to;
determining additional channels that press release can be sent to.

7. Other Business

- a. Update on 75% rule:** There was some movement on this bill yesterday. The coalition leadership is working very effectively. In addition to reduction from 75% to 60%, that would allow more people to be rehabilitated, we are seeking therapy caps through June of 2008.
 - b. New congressional legislation about lobbying:** Council members will monitor and publicize to each other. This applies to any items of interest.
8. Adjournment: The meeting adjourned at 3:40 PM.

Next Meeting: Thursday, January 17th, 3:00 PM Eastern Time.