

**Spinal Cord Leaders Council
Monthly Teleconference Meeting**

**Thursday, January 17, 2008
3PM**

MINUTES

Attendees:

Buhrer, Richard, American Association of SCI Nurses
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
Goldsmith, Beth, Craig H. Nielsen Foundation
Claypool, Henry, ITEM Coalition
Larson, Eric, National Spinal Cord Injury Association
Karp, Gary
Klemme, Karen, American Association of SCI Nurses
Butt, Lester, American Association of SCI Psychologists and Social Workers
Hudson, Lesley, American Spinal Injury Association
McDonald, Chris, Commission on Accreditation of Rehabilitation Hospitals
Polonsky, Dana, Craig Hospital
Gilmer, Tim, New Mobility
Johnson, Mark, Shepherd Center
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

Mr. Tobin welcomed new members, Karen Klemme, Lesley Hudson and Henry Claypool. He also stated that Bruce Morgan had a scheduling conflict, and that Mr. Tobin would report briefly in his absence.

3. Agenda

The agenda was unanimously adopted as submitted.

4. Minutes of 12/20/07

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

5. Committee Reports

Durable Medical Equipment and “In the Home” – Mr. Morris reported that the committee has drawn up draft legislation, which will be further reviewed by the committee, prior to being shared with the entire Council.

Mr. Claypool brought to the attention of the Council a report issued by the inspector general of HHS concerning cost of purchasing power wheelchairs over the Internet. It was reported that the study did not take into account important areas such as assembly and training. ICS has written a letter to the inspector general critiquing the report, making recommendations for improvement, and offering the Council’s assistance. The number of suppliers of power wheelchairs is relatively small; competitive bidding might shrink the market even further. It was pointed out that the issues surrounding durable medical equipment must be distinctly broken down for purposes of Internet posting. Mr. Tobin reported that www.spinalcordleaders.org is now live and that information to the site will be posted in the near future, including a link to the above report with a brief synopsis of the issue. Mr. Tobin thanked Mr. Claypool for his report.

Christopher and Dana Reeve Paralysis Act – Additional sponsors to the bill have not yet been identified. Until such time as that happens, we have been advised to keep hands-off. There will be a role for the Council in the future with passage and implementation of the bill. Paul will contact committee members to see where we are with Senator Harkin, and to determine whether he has met with Senator Coburn of Oklahoma.

Candidate Healthcare Platforms – A draft questionnaire is being reviewed by committee members. The committee expects to finalize and share this document with the Council by the time of the next meeting.

Communications Committee – www.spinalcordleaders.org is an independent site (does not have the branding of any organization); it lists approximately 18 member organizations. The site will function as the Council’s public face to get word out about different campaigns and activities of the Council. Any member organization is welcomed and encouraged to contribute information on policy initiatives and other issues of relevance to the SCI community. Information should be sent to Committee Chair Eric Larson; however, anyone wanting to post things directly can be enabled to do so. We hope the site will become a discussion board for the community to talk about public policy issues. Mr. Tobin requested members to visit the site and to submit suggestions to him at ptobin@unitedspinal.org

6. Other Business

- a. **Social Security – Ways and Means Committee Hearing:** Mr. Weisman reported that he, along with Mr. Terence J. Moakley, who was representing CCD, attended this hearing to oppose proposed rules for

appeals for denials of social security disability. The backlog of cases is 600,000, with average waiting periods of 300-600 days. The proposal would deny ability to introduce new evidence of an exacerbation. The panel was receptive and sympathetic to Mr. Moakley's testimony. We informed SSA we would be prepared to present a classic hardship case if the need arises.

7. **Adjournment:** The meeting adjourned at 3:42 PM.

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