

**Spinal Cord Leaders Council
Annual Meeting**

**Wednesday, November 7, 2007
9:00am – 3:00pm**

**Hyatt Regency Washington on Capitol Hill
Room: Congressional C/D**

MINUTES

Attendees:

Bonninger, David, National Spinal Cord Injury Association
Cahill, Ida, Sam Schmidt Paralysis Foundation
Canose, Joseph, Christopher and Dana Reeve Foundation
Gray, Phyllis, Kennedy-Kreiger Institute
Hathaway, Peggy, United Spinal Association
Johnson, Mark, Shepherd Center
Maher, Pat, National Spinal Cord Injury Association
Morgan, Bruce, Christopher and Dana Reeve Foundation
Morris, Andrew, United Spinal Association
Prokop, Susan, Paralyzed Veterans of America
Roth, Marcie, National Spinal Cord Injury Association
Tobin, Paul J., United Spinal Association
Vance-Lauritzen, Sunny, University of Utah
Weisman, James, United Spinal Association
Wilderotter, Peter, Christopher and Dana Reeve Foundation

I. Call to Order and Introductory Remarks

The meeting was called to order shortly after 9:00am by Paul Tobin. After brief remarks from Marcie Roth and Paul Tobin in which they described the origins of the SCI Leaders Council and the need to formalize the efforts of the Council, Paul Tobin assumed the role of temporary chair.

II. Adoption of the Agenda and Minutes

There were no changes to the proposed agenda and no minutes were presented to the body for its approval.

III. Review, Revision and Adoption of the Bylaws

The Council members present discussed the draft SCI Leaders Council Bylaws that were distributed prior to the meeting. The original and revised bylaws are affixed as Attachments A and B respectively.

In summary, the Council resolved the following items:

- a. The title of the Council shall heretofore be known as the Spinal Cord Leaders Council, eliminating the SCI acronym that was thought to be too restrictive for some of the membership organizations present. There are numerous conforming amendments to carry this change throughout the document.
- b. The purpose in section 1.03 eliminated the listed means by which the Council seeks to improve the quality of life of individuals with spinal cord injuries and disorders. It was felt that the listing was not all-inclusive and that attempting to assemble an all-inclusive list would be restrictive by omission. Furthermore, the “federal” limitation on legislation, regulations and policies was eliminated. Conforming amendments throughout the document reflect this change.
- c. Individuals, while they are welcome to participate on the Council, shall not have equal rights as a voting member of the Council. Conforming amendments reflecting this change are made throughout the document.
- d. Section 3.07 was amended to include committee meetings by teleconference.
- e. Section 3.10 amended the quorum to include the greater of seven (7) primary representatives or 25% of primary representatives, or their respective alternates as a quorum.
- f. Section 3.11 was amended to include that proxies, if they are to be used, must be:
 - a. in writing;
 - b. presented to the Chair prior to the meeting or teleconference; and
 - c. the proxy must direct how the representative would like his or her vote cast on the particular motion to be voted upon.
- g. Section 5.03. The “Chair” was changed to the “Secretariat” in the first sentence to clarify the intention.
- h. Section 7.01 was modified to clarify that minutes and correspondence shall transfer from an outgoing Secretariat to a successor Secretariat within ten (10) workdays following a transfer of leadership by the Council.
- i. Article VIII was added to provide the method by which the Bylaws can be amended or modified in the future.

On a motion by Mark Johnson, seconded by Marcie Roth, the Bylaws of the Spinal Cord Leaders Council were adopted as amended.

IV. Designation of Primary and Alternate Representatives

Each organization present at the SCLC was asked to provide the names of the primary and alternate representatives for the 2007-2008 term:

Organization	Primary Representative	Alternate Representative
Christopher & Dana Reeve Foundation	Bruce Morgan	Joseph Canose
Kennedy-Kreiger	John MacDonald	Phyllis Gray
NSCIA	Marcie Roth	Pat Maher
Paralyzed Veterans of America	Susan Prokop	Lee Page
Sam Schmidt Paralysis	Ida Cahill	M. Johnston

Foundation		
Shepherd Center	Mark Johnson	James Shepherd
United Spinal	Peggy Hathaway	Andrew Morris
University of Utah	Sunny Vance-Lauritzen	Trish Jensen

V. Appointment of a Chair and Secretariat

For the 2007-2008 term, Paul Tobin volunteered to serve as Chair and offered the administrative support of United Spinal Association as Secretariat. With no other volunteers, the appointment carried by acclamation.

VI. Establishment of a Standing Schedule

After some discussion regarding the time, the standing schedule for teleconferences shall be the third Thursday of each month at 3:00pm ET.

Note: All teleconferences of the SCLC can be accessed by calling 888-617-3400, passcode 954868.

The decision to appoint a Nominating Committee at this point was tabled until a future teleconference with more representatives.

VII. 2007-2008 Policy Agenda Discussion

The Council reviewed the areas that were identified at the 2006 SCI Summit as policy priorities. These areas were:

- A. Assistive Technology
- B. Community Living
- C. Health Promotion
- D. Rehabilitation
- E. Research

The Council then developed lists of current concerns under each of these topics through a nominal group process.

1. Assistive Technology

75% Rule
Association w/ Complications and
Prevention of Secondary
Competitive Bidding
Cost
Durable Medical Equipment
Employment
In the home
Innovation & Development

Medicare
Nanotechnology
Partnering
Research & Development
Training
Transfer Technology
Universal Design
Voting

2. Community Living

Education
Community Choice Act

Personal Assistant Services
Entitlement reform

Housing
ADA Restoration
Voting
Get out the Vote
Transportation
Taxi
Models of Community Living
Funding
Employment
Social Security
Universal Design
Recreation
Civil Rights
Children's Issues
Reproductive Rights

3. Health Promotion

Telehealth
Wellness
Access to rehab
Competitive Bidding
Access to Healthcare
75% Rule
Sports & Rec
Pharma
Specialty Services
State based Medicaid limits
Medicare 2 year waiting period
Consumer Protection
Traumatic Brain Injury
Education
Clinical Trials
SCHIP
Caregivers
Accessibility
Research

4. Rehabilitation

VA SCI System
Habilitation
Defining the population
New-Branch
Peer Mentoring
75% Rule
Standards of Care
Evidence Based Practice

Funding for Daily Living
Emergency Preparedness and
Management
Coalition Building
Independent Living Centers
Network
MFP
Veterans
Caregivers
Immigration Issues
Raising Awareness of what is out
there
Life Care Planning
Worker Pool
Parents' issues

Advance Directives
Comprehensive Health reform
Public and Private Insurance
Evidence Based Practice
Multi-cultural outreach
Access to DME to minimize 2ndry
conditions
Transparency of Medicaid Waiver
Rehab Act Reauthorization
DD Act Reauthorization
Portability
Mental Health Parity
Defining the population
From DD to D
Immigration Status
Assisted Suicide
Prevention
Cost
Inequity

Education
Access to Primary
Immigration Status
Model Systems
CARF
Access to Secondary
Recreation
Length of Stay

State Limits
Outcome Measures
DME Delays
Voc Rehab

Caregivers
Worker Pool
Research~
Inequity

5. Research

Standards of Care
Legislation
Funding
Collaboration
Interstate Research Collaboration
From Bench to Bedside
Community Living
Clinical Trials
Public Awareness
Stem Cells
Activity Based Therapies
Private \$\$
Advocacy

Technology
Quality of Life
Basic
International Issues
NIH funding
Knowledge of Clinical Trial Issues
Caregivers
Shortage
Communication
Hypothermia
Gene Therapy

Paul Tobin then asked that each person pick the issue of paramount importance to their organizations and its constituents. The Council then began a process, from which three committees emerged as focus areas for 2007-2008:

- Durable Medical Equipment and “In the Home”
 - a. Committee members: Andrew Morris (Chair), Marcie Roth, Lee Page and Ida Cahill
- Christopher and Dana Reeve Paralysis Act
 - a. Bruce Morgan (Chair), Marcie Roth, Mark Johnson, Susan Prokop, Sunny Vance-Lauritzen and Andrew Morris
- Candidate Healthcare Platforms
 - a. Marcie Roth (Chair), Peggy Hathaway

The Chair of each of these committees will develop the enabling charge for the committee, along with timelines and benchmarks that will indicate the degree of success for the committee and the council. Others who were not present at this meeting will be welcomed to join committees and a call for additional committee members will be put forth at the November 15 teleconference.

Additionally, the Council will be seeking assistance with the formation of a Communications Committee to convey the mission and achievements of the Council. This item was tabled until the next meeting.

VIII. Adjournment

Having no other business before the Council, the Council adjourned at 1:30pm. The next meeting will be Thursday, November 15, 2007 via teleconference at 3:00pm ET.

Attachments:

- (A) SCI Leaders Council - Bylaws - Draft 3.doc
- (B) Spinal Cord Leaders Council - Bylaws - Adopted 11-7-2007.doc
- (C) 71107 SCLC Roster.xls