

GBS/CIDP Foundation International
Denver Chapter Newsletter

Issue Number 14 --- Winter, 2007

Looking Back:

Our December potluck was informative and productive for those who attended. Thank you to Fran Kirk for handling the reminder calls this time. In a brief business meeting the group voted for a 2007 schedule of four meetings: the first Saturdays in March, May, October, and December. (Note: We are going back to our original, voted-for schedule.)

On December 15, 2006, a fundraiser was held by the Gay & Lesbian Community for the Foundation. Ann and Elaine were honored to be present along with George and Bob. A sizeable check was sent to the Foundation.

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Foundation News:

The Foundation is seeking support of a bill that would allow Medigap insurance for those disabled by GBS. Symposium attendees signed a banner that will be presented in Washington in 2007.

When any of us attends the International GBS/CIDP Symposiums, we try to bring back as much information as we can, but when specialized topics come up such as relapsing GBS compared to recurrent residuals, we need in depth discourse grounded on current research. Various speakers used to be recorded at their workshops and they were important tools to share with the rest of our group. Unfortunately, these tapes are no longer available, so we rely on information shared directly at our meetings.

Our November meeting was one such occasion where we learned about recent advances in identifying variants. Ted Asch wrote up and shared some good notes which are posted on the new web site.

We have a new DVD from the Foundation explaining the diagnosis and treatment of CIDP. It is about 20 minutes long and we plan to show it at a future meeting.

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Current Local Issues:

There are still some handouts left describing the overall symposium experience as well as information on current issues affecting the GBS/CIDP community. They will be available at the next meeting.

Volunteers for various jobs are beginning to come forward and their interest and efforts are greatly appreciated.

Most needed right now are people from various parts of the Denver metro area to distribute GBS information to hospitals and rehabilitations centers on a periodic basis. Please consider "adopting" one or two facilities, providing them with current information and checking back with them on a regular basis to make sure someone on staff in a spell of over zealous housecleaning did not mistakenly throw away our information.

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Looking Ahead:

The first meeting of 2007 will be at St. Anthony Central, 4231 W. 16th ~ near Colfax and Sheridan. Mark your calendars: SATURDAY MARCH 3, 2:00PM. Speaker to be announced. Your presence and input at a meeting will always help another GBS survivor.

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Living Well with GBS/CIDP:

Slow and Steady: Life after GBS ~

Once the healing process has begun, we face a new challenge: pacing ourselves and using our energies wisely. For years, doctors have been cautioning patients to avoid pushing themselves to the point of fatigue. Many of us know how difficult it is, however, to resist the urge to dive into activities we've missed during the weeks and months following diagnosis. The body will exact its price, as two of our members have found these past few months. Elaine Sparrow, whose GBS occurred in 1966, was continually

cautioned by her doctors and says that curbing her physical activities was one of the hardest parts of recovery. Many GBS survivors can attest to the fact that when we overdo we often don't feel the consequences until the next day or even several days later. Our bodies talk to us and we need to listen. The human body is a wondrous machine that heals in its own time. We're all familiar with the story of the tortoise and the hare. GBS is another example of how slow and steady wins the race. As Dr. Joel Steinberg of the Foundation might say, "Sit down before you fall down." A hint: Remember when you were young and how good it felt to take a nap? We all need to give ourselves permission to take a nap. Naps are good at any age!

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All recipients of this newsletter are encouraged to provide suggestions and tips for upcoming meetings and newsletters. This is YOUR way to provide encouragement and HOPE to others. We need YOUR input so we can to continue to provide you with what you want from this group.

Please call or write us:

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Be well, stay warm, and we look forward to seeing you in March.