

# **ROSEVILLE PARKINSON'S SUPPORT GROUP**

## **April 2009 MEETING MINUTES**

The April meeting began with the announcement of several upcoming events of interest to members of the Roseville Parkinson's Support Group (RPSG). 1) Stormy announced that the Parkinson's Association of Northern California (PANC) will hold its annual Auction for Action fund raising event at the Scottish Rite Temple on September 12<sup>th</sup> from 5pm to 9pm. This year's event is entitled "A Cruise for a Cure". 2) It was announced that RPSG will have a booth at the City of Roseville's "Downtown Tuesday Night" event. It is our goal to educate the public about Parkinson's disease. We will pass out RPSG flyers, a shopping bag and sell bumper stickers with the slogan, "I Support Parkinson's Research". 3) Tara informed the group that we will also be participating in the Citrus Heights Health Fair taking place on Saturday May 16<sup>th</sup> at Fountain Square from 9am to 1pm. 4) Discussion was held regarding the opportunity for RPSG to participate in several fund raising events such as selling tickets to a Capital Stage theater performance where RPSG would receive a profit based on the number of seats sold, and holding an evening at Fuddrucker's Restaurant where we could receive 20% of those proceeds earned from flyers used to purchase food.

Tara announced that the John Argue Parkinson's exercise class will be on summer hiatus from June through September. Class members are working on an alternative site. Hopefully something can be worked out.

A copy of the RPSG fiscal report and the current by-laws are available to members upon request. Please email or phone any Board member if you would like a copy.

Tara outlined the 2009 RPSG objectives. They are:

1. Having our website rebuilt,
2. Continuing our "John Argue" exercise class and providing 50% reimbursement,
3. Providing snack reimbursement (\$20 max.).

On March 12<sup>th</sup> the Parkinson's Institute's "Victory Summit for Parkinson's Disease" was held in San Jose. Members John Springer and Harry Butler attended and provided a brief summary on several of the topics presented at the summit:

1. "23andMe" is a program that allows individuals to obtain their genetic history. The \$400 price will temporarily be reduced to \$25. The reduction

in cost is due in part to the fact that Sergey Brin, the co-founder of Google, has agreed to underwrite the program.

2. The history of DBS procedures and what the future holds were discussed.

Aaron Washington, from Vernalis Pharmaceuticals made a presentation regarding the PD drug Apokyn. Apokyn is a medication that is delivered with a very thin needle (just under the skin). It is meant to be used with your PD oral drugs as needed to treat off episode motor symptoms such as muscle stiffness, slow movements and difficulty starting movement. Apokyn can be used up to 5 times a day and lasts approx. 90 minutes.

Harry Butler, RPSG Treasurer, reminded us that the 9<sup>th</sup> annual “Parkinson’s Seminars at Sea” will be departing from Long Beach on October 18<sup>th</sup>. The cruise is to the Mexican Riviera, and features workshops and presentations by movement disorder specialists including John Argue. The cruise is geared toward PD patients and caregivers. Those who are interested can call Harry at (916) 726-1573 or email him at [www.hapbutler@comcast.net](mailto:www.hapbutler@comcast.net) .

Dorothy Titus highly recommends the book, “Surviving Your Spouses Chronic Illness”, by Chris McGonigle. Dorothy feels the book is invaluable.

Randy Calvert again stressed the value of the website [www.patientslikeme.com](http://www.patientslikeme.com) which can be used to compare experiences.

Shelly Butler, Secretary.