

San Diego Central County Parkinson's Support Group
Minutes of the Monthly Meeting of the Board of Directors
August 12, 2019

Location of Meeting:

County of San Diego Health and Human Services Agency
3851 Rosecrans Street, San Diego, CA 92110
San Diego Room

Present at Meeting:

Nancy Floodberg, , Tony Jeske, Deborah Jordan, , Debbie Stubbe, Dolores Cohenour, Jodi Harrison (via ZOOM)

Initial Directors of SDCCPSG

Nancy Floodberg
Tony Jeske
AnnD Canavan

Officers

President – Nancy Floodberg
Vice President – Jim Paterniti
Treasurer – Tony Jeske
Corresponding Secretary – Deborah Jordan
Recording Secretary – Dolores Cohenour

Directors

Grant Writer – Jodi Harrison
Newsletter Editor – Jodi Harrison
Reporters – Dolores Cohenour, Jane Granby
Newsletter Publisher/Distributor – Nancy Floodberg
Publicity – Dolores Cohenour
Social Media – Bruce Lowe
Videographer – Ron Phillips
Webmaster – Bruce Lowe
Webmaster, Jr – Jesse Luna
Hospitality calls – Sharon Hieserich

Open Positions

Technical Support
Technical Support Jr.
Fundraising
Event Photographer

The fifteenth meeting of the Board of Directors of the San Diego Central County Parkinson's Support Group (SDCCSPG) was called to order at 10:05 am on August 12, 2019 at the County San Diego Health and Human Services Agency located at 3851 Rosecrans Street, San Diego, CA 91110 – San Diego Room by President Nancy Floodberg. Tony was official timekeeper.

Approval of Minutes and review of Agenda/Updates

The Board approved the July Minutes and the Agenda for August as written.

President Nancy Floodberg set up the ZOOM meeting successfully and there was a discussion about having Bruce Lowe write up a description on how to log into ZOOM. There was a consensus yes vote to have the Barfells and the Hoveys attend the Breakout meeting via ZOOM.

The consensus is to keep the live Board meeting once a month. Anyone who cannot participate may use Zoom rather than attend the meeting live.

Dolores compiled a To Do List from the board meeting minutes that will be incorporated on the last page of the minutes. Nancy will italicize the tasks that still need to be completed.

Jodi Harrison, our Newsletter Editor and Grant Writer, will remain in San Diego. Her house has been sold and she is moving into an apartment and will stay active in our support group.

Deborah Jordan is the Corresponding Secretary and the Librarian for our support group.

Old Business

Nancy Floodberg

Contact Forms

Nancy will send out a final request for the Contact Information Form to be filled out in the beginning of September. It will include a downloadable form as well as a link. Members can also call Nancy to verify that they have already filled out a Contact Information Form with the proper information. There are two issues: the box is not being checked indicating whether or not they want to be in the Directory, nor do they check how they want to receive their newsletter. Nancy has noted what is missing on the side of the Contact Information Form. Nancy has given Tony the written forms after she has inputted them manually. Copies will be given to Deborah Jordan and Deborah Stubbe to call for the missing information.

Google Calendar

Bruce has not yet resolved the printing problem with our account's Google calendar.

Update on Welcome Packet and Resource Guide

Nancy is still working on the Welcome Packet's Resource Guide. Nancy will meet with Susan Howard next week. Susan was out of the country and her return was delayed by her husband's illness. The Welcome Pamphlet is the trifold that we were able to reduce down 8.5 x 11 and will be uploaded onto the Parkinson's Association's website as a downloadable.

Pacific Beach Support Group Chapter

Lee Carver and Susan Churchill attended the Pacific Beach Support Group meeting along with two persons from Wesley Palms. Nancy had a discussion concerning how we, as a county community, are going to deal with all the residential communities that want us to have support groups at their locations.

La Jolla - Monarch Cottage

The Marketing Director for Monarch cottage sent Nancy potential support group dates for the beginning of the month. Jim Paterniti wants to participate. They are going to tour Monarch Cottage and have a conversation about exactly what their support group might look like, if they are willing to host it and provide lunch. Our biggest concern is transitioning people from the buses in and out and Monarch said they will take care of it. Either the delivering agency or Monarch has to be responsible for the people, including transitioning in and out of the building. A planning meeting is scheduled for this Thursday.

Tony Jeske

Audit

The recorder has been purchased and delivered. We still need somebody to help with the audit. Peter Key's name was mentioned but, according to Nancy, he is out-of-town for two weeks. The audit needs to be done by a non-board member. Nancy stated that we should reach out to Peter to see if he is willing to do it. There is no time-limit on doing the audit. There was a suggestion to include the monthly money spent and balance in the minutes. Tony said it was easier to just include a balance sheet and Nancy requested that it be emailed to her.

President's Report Nancy Floodberg

Parkinson's Foundation

Chris Buscher is very interested in CARR's pilot project. See below.

Parkinson's Association

Nancy is meeting with the Parkinson's Association tomorrow and with Chrisy Selder and Chris Murphy from CARR (Consumer Advocates for Residential Care for the Elderly Reform). Chrisy sent Nancy a pilot project about a month and a half ago. The project is to develop a program to train residential care facility administrators and formal caregivers on how to care for a person with Parkinson's residing in their facility. Once training is completed, the facility would get an emblem on CARR's website next to their business name, Parkinson's Partner, for example. If you or a loved one has Parkinson's, and are looking to move into residential community, you are going to go to the places that have had the training. Initially Chrisy said that she and Nancy might provide the training, but it does not have to be limited to the two of them. There are other people in the

Parkinson's Association that are well trained and well skilled like Marty Acevedo or Kathy Bruyere. The trainers are persons who are in the trenches living with Parkinson's, and in and out of the hospitals. CARR was founded 10 years ago by Chris and Chrisy who met in graduate school when they were getting their master's in Gerontology. They have developed a nonprofit foundation that oversees all the care facilities in San Diego County, which are listed on their website. You can go to their website to see what complaints had been registered, and who's who doing what. And CARR is licensed by the state to do the training.

We are moving forward with the Parkinson's Foundation Aware in Care training and the site has been selected here in San Diego. Edna Culp, who is San Diego's Aware in Care team and a UCSD advanced nurse practitioner, went back to Rochester for her training. There are five currently on the San Diego team. Teams throughout the nation have a monthly video conference with the Parkinson's Foundation and at the last one two people in the Midwest/East Coast areas expressed interest in our DUOPA Therapy support group. One is considering Duopa therapy and the other's husband already has it. Nancy was put in touch with them by the Foundation, however, has not received further response from either. Current focus of the team is distributing the Aware in Care kits countywide.

Nancy received a letter from Ted Thompson, of the Michael J, Fox Foundation, regarding the California Parkinson's disease registry because there was a sunset provision to shut it down on January 1, 2020. Because of the short turnaround time, Nancy signed it without bringing it to the Board. Marty Acevedo, a person with Parkinson's who sits on the Parkinson's Association Board signed it, as did somebody in Orange County and in San Francisco. It was then sent to the state legislature in support of maintaining California Parkinson's disease registry.

The Sunset Soirée, slated for October fifth. is on tract. It will be different than last year's that had a full sit-down dinner. This year, there will be restaurants with featured areas where you can go and sample their creations. Perimeter seating will be \$250 and seating at a table is \$500. The Soirée will be advertised in the newsletter.

Empowerment Day is going to be held on Friday, November 15th. Last Empowerment Day, Debbie Jordan did an exceptional job of reaching people on the premise's walkways and vendor areas, some of whom were in crisis. Lisa Stinchcomb has contacted the County of SD Access and Crisis Line and staff member, Mary McKinnon-DuBois will staff a support table at Empowerment Day. There will be volunteers, in specialty shirts, directing people as to where they need to go. We all need to watch and look for anyone in need. Debbie Jordan will do the staffing and perhaps Debbie Stubbe.

Life Walker Update

The ProtoStar company who makes the LifeWalker is moving to a new location in San Diego. Nancy will contact them for their new address and give it to Dolores, so we can send a thank you card or professional letter for the fifteen plus LifeWalkers they donate to us for free. Mike Moore faceted Nancy and asked about having a LifeWalker sent to him. Nancy called Shelly Federhart, ProtoStar's rep, and she said they have refurbished UpWalkers and might be able to send one out.

SDCCPSG

- **ZOOM Consulting and Script**

Nancy is going to ask Bruce if he could write a ZOOM script instructing a new user in how to operate the program. Bruce would write a little description on how to log on and use ZOOM, which Nancy would send to the Barfells and Hoveys, support group participants who no longer reside in San Diego, but might like to attend a support group via ZOOM.

- **Librarian**

Deborah Jordan has filled the Librarian's position. She is in charge of monitoring books coming in and out. The Librarian transports the books back and forth to the meetings. A sign in and out sheet will be used for our library books. A time limit will be set for how long a book can be out and Deborah Jordan will send out a reminder for overdue books.

- **New Library Books**

Nancy recently purchased two more books which she is going to donate to our library. One of them is "*Don't Rain on My Parade; Living a Full Life with Alzheimer's and Dementia*". The other book is the "*The Long Moment*", about caregiving a person with dementia.

- **August Potluck (Friday, August 16th) at ZLAC Rowing Club**

The nutrition company out of Arizona will not be providing dessert at the Potluck. One of their partners is having an unexpected surgery. Debbie Stubbe will buy a commercial dessert and Tony has approved the expenditure. We are going to raffle off a LifeWalker.

- **Speaker Series**

Dates for this Fall's Speaker's Series are Sept. 11, Oct. 9, and Nov. 13. Jim was unable to find out if Dr. Paceto is available this Fall to speak on sleep disorders as he is on medical leave for the next month. Nancy tried to contact Dr. Kunkel, a gastroenterologist (bowel function). She spoke to his secretary who needs to get back to Nancy. Nancy will call his office again.

At the last Friday's Parkinson's Association meeting, David Chong of Coast Care Partners spoke. Nancy had a meeting with representatives from the company, who have been awarded part of the Health and Human Services' Respite Well million-dollar contract supporting those living with dementia in San Diego county. Through the project, Coast Care provides discounted county respite, and day program care for those living with dementia. They also provide regular care and can provide information on the Veteran's Aid and Attendance program. They are going to be the speaker for September Speakers' Series.

Newsletter/Calendar

For the August Newsletter, Tony will be interviewed by Dolores. Jane Granby will write her own interview for the September issue. Nancy is having issues with printing the Google calendar and is waiting to hear back from Bruce on this issue.

August Calendar – There is a tentative date on the calendar for August 1st for the Monarch

Cottage meeting, but that does not mean it will happen. The calendar is pretty light this month as Nancy could not find any community events hosted by caregiver organizations, coalitions or attorneys. The July calendar had the time listed for Pt. Loma's Breakout as 9:00AM (a holdover from when Flying Solo met just prior to Breakout). It was corrected and listed in the August calendar as 10:00AM. In July, August's Board Meeting was listed as occurring in the San Diego Room. It was corrected to the University Room.

Bruce asked Nancy if she wanted all the meetings noted in the Google Account calendar, so it was all in one place and she said yes.

Support Group Leader's Reports

- **Speakers' Series**

For the Sep 11th Speakers' Series, David Chong, Executive Director of, Coast Care Partners will present on Navigating the Senior Care Landscape. In addition, others from Coast Care will speak on the county's new Respite Well program, as well as the Veteran's Aid and Attendance program.

- **PLPSG**

We have three new participants; Robert Oaks, who came through the Parkinson's Association and is a Duopa therapy user, and Sandy & Jack Marshall. Jack was recently diagnosed with Lewy-body dementia in his 1st year of Parkinson's.

- **PBPSG**

Lee Carver and Susan Churchill, the couple that attended our meeting, also attended the Pacific Beach Support Group meeting as well as two persons from Wesley Palms. There is concern as to how we, as a county community, are going to deal with all the residential care facilities that want us to provide support groups in their facilities.

- **Do you DUOPA?**

The Duopa Therapy support meeting went very well. The pharmaceutical ep drives down from Riverside each time to join the meeting. There is so much technical information regarding the pump that it is actually become a really helpful venue for addressing potential issues. Mike and Cindy Moore, who moved to New Jersey, attended the meeting via ZOOM. The pharmaceutical company, Abbvie, is having a presentation on Wednesday at Phil's BBQ Event Center which includes a free dinner. Nurse practitioner, Sherry Gould, will be there, as well as a person with Parkinson's who is living with Duopa therapy. Nancy is sending a flyer out with registration link included for anyone interested in attending.

- **Flying Solo**

SDCCPSG's Flying Solo has consolidated with UCSD Network's Flying Solo, a subgroup of UCSD's Mission Valley Support Group.

- **Veteran's**
Ron Phillips has not updated Nancy regarding the group's status.

New Business

Tony

Financial

We received a donation of \$100.00 from the Jesse and Fari Luna. Our balance is \$7,320. If we are going to provide an Annual Report to members, a copy of the P and L in the monthly newsletter, then we do not have to include finances in the newsletter. Once a year we could hold a general meeting to talk about what is going on and hand out the Annual Report, list where we expended money, look back at what we have done and look ahead to what we will do next year. The fiscal year ends in January which would be a good time to do it.

Stationery

We need to modify the stationery; the names are not the same anymore. Tony will send Nancy a copy of the old stationery and Nancy will modify it and get it back to Tony. Nancy will forward the stationery to Dolores for the thank-you letter.

Sharp Health System New Movement Disorder Specialist

There is a new neurologist at Sharp, Dr. Angeline Jocson, MD who, according to Acadia pharmaceutical rep, Lisa Stinchcomb, is not a Movement Disorder Specialist. She will check further and get back to Nancy. *Update: Dr. Jocson is a Movement Disorder Specialist, the first and, currently, only one in San Diego's Sharp Health System.*

Debbie Jordan

Overdue Reminders

Debbie Jordan is having Dolores make Library reminder cards on her computer. Dolores needs to print out the card and get it to Debbie Jordan so she can send the reminders for the 4 overdue books and finish alphabetizing the library's books.

Contact Forms

Debbie needs to make calls for the contact forms. Nancy said she sent everyone an excel spreadsheet with participants' contact information. Nancy will send Tony an updated version of the spreadsheet which he will print out for Debbie Jordan.

Snacks

Debbie will provide the snacks for the Speakers' Series on 9/11 since Debbie Stubbe is out of town.

Bruce

Zoom Script

Nancy will talk to Bruce to see if he would be willing to write a description on how download, log onto and use ZOOM, which Nancy would send to the Barfells and Hoveys.

Google Analytics

Nancy emailed the Google Analytics to the board members since Bruce could not attend the meeting. Two of the analytics are essentially the same and only one contains additional information on where our sites' visitors originate. Next, is the highest number of viewers. On the first page there are spikes for July 18th with 18 viewers, August 1st with 14 viewers, and 38, the very highest, occurred when Bruce went to print the report. Jodi notice that when we send the newsletter, we tend to get a burst. The second report shows which pages were visited the most often. The potluck sign-up page was visited 152 times, the calendar 62 times, Parkinson's Hacks 56 times, and the Speakers' Series 28 times, etc. The last page indicated that no searches were made this past month. Bruce stated that he made several searches, so something is not right. The percentage of new visitors was higher than the percentage of returning visitors. There were 177 visitors from the United States, foreign visitors included: China 3, Mexico 3, United Arab Emirates 2, UK 1, Israel 1, Nigeria 1, and the Philippines 1.

Dolores

Water

Dolores will bring water for the 9/11 and 9/23 meetings.

Thank You Notes

Dolores received the stationery from Nancy to create a thank-you note for Protostar's LifeWalker donations.

Nancy

Contact Forms

Nancy needs to update the written forms with Mr., Mrs., Miss and sent out a final request for the Contact Information forms.

Welcome Pamphlet

Nancy needs to talk to Bruce about uploading the pamphlet to our support group website. The Resource Guide needs to be finished and labels printed for the envelopes. We also need to have an envelope stuffing party.

Business Cards

We need a generic business card that grabs you attention for the San Diego Central County Support Chapters and on the backside says, "Come Join Us." For the next meeting we need to put our heads together to design a card. (Dolores) Have a logo or picture at the bottom near Nancy's contact information and the support group website. (Nancy) But not the main center of attention so that all the person sees is the person's name and not something about the support group. Have a catchy

phrase such as “You have Parkinson’s –You are not Alone.” Jodi suggested a quote from Winston Churchill, “Never Give Up,” while Nancy suggested “Live Well with Parkinson’s.” Nancy needs to send Dolores copies of UCSD’s and North County’s business cards. Our VistaPrint account has closed because we have not used it for 60 days. As a result, any business card reorders will have to be redesigned.

Cards Purchased from the Support Group Fundraiser

Nancy will provide Tony with a receipt for reimbursement of the \$30.00 used for purchase of a box of Thanks and Blanks cards for our Corresponding Secretary. This was part of a fundraiser conducted by Nancy’s daughter, Tessa LaPointe, who plans to donate the proceeds to SDCCPSG. Once received, we need to send Tessa a thank you note.

Smart Agenda

Nancy will talk to Susan Howard about it when she returns from traveling in October.

The meeting was adjourned at 11:58 am.

The next board meeting will be Monday, September 9th, at HHSA in the San Diego Room.