

San Diego Central County Parkinson's Support Group
Minutes of the Monthly Meeting of the Board of Directors
July 8, 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, Bruce Lowe (via ZOOM), Debbie Stubbe, Jim Paterniti (via ZOOM), Jesse Luna (via ZOOM)

Initial Directors of SDCCPSG

Nancy Floodberg
Tony Jeske
AnnD Canavan

Officers

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

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 fourteenth meeting of the Board of Directors of the San Diego Central County Parkinson's Support Group (SDCCSPG) was called to order at 10:07 am on July 8, 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 Minutes and the Agenda for July as written.

President, Nancy Floodberg, set-up the ZOOM meeting successfully, using our newly purchased account. There was discussion on how the procedure works with ZOOM in place at the meetings. Bruce Lowe, Jim Paterniti, and Jesse Luna attended the meeting via Zoom. Nancy and Bruce resolved Jesse Luna's problem logging into ZOOM.

Jodi Harrison is currently in the hospital and will not be present at the meeting. She sold her house may be moving to join her daughter on the East Coast. Whether she moves or not, Jodi still plans to be active as our Newsletter Editor and Grant Writer all of which can be accomplished via email.

Mike Moore and his wife, Cindy, moved to New Jersey. Mike's brother and planned caregiver had a heart attack, so Mike is now being cared for by his parents while Cindy works. Mike is attending Rock City Boxing, an hour's drive from his home. There is a possibility that Mike and Cindy may attend DUOPA Therapy Support Group meetings via ZOOM.

Old Business

Nancy Floodberg

Contact Forms/ Directory/Google Account

Nancy is not receiving Contact Forms that are properly completed. There are two issues: the box is not checked indicating whether or not they want to be in the directory, nor do they check how they want to receive their newsletter. The paper form does not ask for a title (Mr. or Mrs.) while the online form does. Nancy needs to update the written form with the titles. Bruce suggested that to improve the response to the prefix, move the prefix choice closer to the top of the contact form. Nancy will work on that. Written contact forms will have to be inputted manually into the Google Account. Nancy will send out a final request for the contact forms to be filled out. It will include a downloadable form as well as the message: *If you want to be part of the directory please go to this link and enter your information.* Members can also call Nancy to verify that they have already filled out a Contact Information Form with the proper information. Tony had a question about the contact database having two email addresses entered separately, one for the person with Parkinson's and the other for the caregiver, and how they will come together. He was not sure how they will come together, but Jodi assured him that they will be paired.

ZOOM Account

Nancy read everything Tony gave her on "How to Setup Your Zoom Account". Bruce reviewed it and stated that we do not need any of the added "doodads". Our ZOOM is now setup on Nancy's computer with no time or participant limits.

Old Business (cont'd)

Name Tags

Nancy was hoping to print them today after meeting with Jodi to set up the template, however, this has been postponed due to Jodi's hospitalization. Nancy is hoping to have them by Wednesday.

Update on Welcome Packet and Resource Guide

Nancy met with friend, Susan Howard, a former teacher, administrator, and private school board member, who is skilled in conveying information. Susan reviewed the Welcome Packet and the Resource Guide.

Due to the possibility of information overload, Susan and Nancy made all the necessary changes to both items which reduced their volume and made them more concise. The pamphlet was reduced from 8 ½ by 14 to 8 ½ by 11 and now prints more easily on our printer. It will be uploaded to the Parkinson's Association website for visitor downloading. Susan also recommended that a separate Resource Card be developed, printed on card stock with a magnet for hanging, to include all the SDCCPSG Support Groups and when they meet. Nancy needs to finish the Welcome Packet and Resource Guide.

Pacific Beach/La Jolla Support Group/s

The PB group at Oakmont had only two persons attend the June meeting, and is considering moving the meeting from the Activity room to the Reading room where it is quieter and more intimate. The meetings will be left intact until La Jolla Group meetings can be set up at Monarch Cottage and the Oakmont members transported to La Jolla either by Oakmont or by FAST. Jim will co-facilitate with Nancy. Jim and Nancy are planning to set up the 1st meeting tentatively on Aug 1 from 11:00am to 1:00pm (first Thursday of the month). Lunch is included and provided by Monarch Cottage. The support group name approved by the board for the newsletter was the La Jolla Luncheon Meeting. After that the Support Group chapter can vote on its own name. Nancy has not heard from the Director of Wesley Palms, a residential community in Pacific Beach, regarding their stated interest in a support group, and will speak with resident, Barbara Anderson, a PwP who suggested it.

Tony Jeske

Name tags distribution – not distributed yet.

ZOOM – Nancy and Bruce successfully set up Zoom for the July meeting with three participants using ZOOM for the meeting.

Photoshop – 2 left to distribute.

Old Business (cont'd)

Bruce Lowe

Facebook

SDCCPSG has a presence on Facebook. Initially Bruce formed both a Page (Pages are for businesses, brands, organizations and public figures to share their stories and connect with people), and a Group (Groups choose topics they'd like to explore and share them with people who share the same interest). Within a Group, participants can talk about and spread the word on what it is doing. It is active and SDCCPSG has little input. As we are not at that stage yet, for now the Group site is gone.

President's Report

Nancy Floodberg

Parkinson's Foundation

The Parkinson Foundation Moving Day Walk, held on June 22nd, 2019, was not as successful as hoped. The Foundation, using the same vehicle for fundraising (the Walk) as the Parkinson's Association, has created confusion in the community and distance at the administration level.

Parkinson's Association

The Association prefers to maintain a separate role from the Foundation as the Foundation tends to brand that to which they donate. A case in point is the Tremble Clefs recent flyer featuring only the Foundation, even though others, including the Parkinson's Association, donated to them. This gives the impression that the Foundation is the only one donating, as well as creating confusion within the community as to the difference between the Foundation the Association. At present, the Parkinson's Association has made the decision to not apply for Parkinson's Foundation grants.

The Good Start Program is slated for Tuesday, July 16st. It will be held at the United Church of Christ on 5940 Kelton Avenue, La Mesa. Nancy cannot attend, however, Debbie Stubbe and Debbie Jordan will be at the shared Support Group table. Nancy will give Debbie Stubbe the handouts, her business cards and either a new trifold or Parkinson's letter.

The Gala (Sunset Soiree Fall Event) will be held on October 5, 2019 at the Del Mar Plaza. Baseball great, Kirk Gibson, a PwP, will the headliner.

Empowerment Day is Friday, November 15th, 2019.

LifeWalker Update

The company is staying in San Diego, but moving to a new location. There are now three versions of the walker; the Life Walker, Up Walker and Up Walker Lite. They have 15 boxed LifeWalkers, and several additional ones that are boxed but not banded, as they were never

President's Report (cont'd)

inspected. None come with a warranty, but all are new and free. Nancy and Chris Buscher plan to pick them up, distribute some to other group leaders and have the remainder stored at the warehouse of Senior Move Masters until others express a need.

SDCCPSG

- **ZOOM**

The meetings are being recorded on audio and video by ZOOM. The audio portion is sent to Dolores where she uses it to develop the minutes. Any questions on what has been written down can be doubled-checked on audio.

- **Librarian**

Nancy would like to have a Librarian in charge of monitoring books coming in and out and is actively looking for someone to fill this position. It would be at an "at large" position where the Librarian transports the books back and forth to the meetings.

A sign in and out sheet will be used for our library books. We have had a book out for 6 months or more and a request or reminder needs to be sent to return the book. A reminder card has been designed by Debbie Jordan and it will be sent out for overdue books. Debbie Jordan is going to do an inventory of our books, as well.

- **New Library Books**

Nancy listed a new book in our upcoming August newsletter that we do not presently have. She wants to purchase that one and the companion book, one for the person with Parkinson's and the other for caregivers. She would like to purchase the first book entitled *Everything you need to know about living with Parkinson Disease* by Lianna Marie. It costs about \$15 to \$16 dollars and eventually purchase the companion book for caregivers by the same author. Purchase of both books was unanimously approved by the Board. Tony suggested that if we had an annual budget for books, we could just order both books at once.

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

Nancy will send a Potluck flyer by the last week of July which will give everyone two weeks until August 16th to sign up. She will make up a flyer and Bruce will give her the link to take us to the website page for the sign up. The flyers will say BYOB (there will be non-acholic back-up), Main Dish, Side Dish, or Salad to share. An Arizona Parkinson's & Nutrition company is bringing dessert. Nancy will work on the flyer and have it done by the time Bruce returns. She will send Bruce the flyer in Word and he will convert the flyer to a PDF format and then insert the hyperlink so it will be active. If the link is put into Word and then converted to PDF, it will not be active.

President's Report (cont'd)

- **Speaker Series**

Dates for this fall's Speaker's Series are Sept 11, Oct 19, Nov 13. Jim was unable to find out if Dr. Paceto is available this fall to speak on sleep disorders as he was on medical leave for the next month. He will try to contact him again.

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.

Accessing Mobile Medical Services (denture, x-ray, lab, podiatry), Nancy can get at anytime to speak at our Speaker Series but would rather give the first right of refusal to Dr Kunkel and Dr. Paceto at Scripps, referred a person in another support group to Michelle Sexton, ND, a Naturopathic Physician who specializes in CBD research and is on staff at UCSD. She might be a viable speaker and Nancy has received a lot of articles about CBD, which is generating a lot of interest. Michelle is based in scientific research and can fill us in on what is happening. Jim Paterniti will talk about the legalities of traveling with CBD on our Travel Series on Wednesday.

Nancy has been contacted by Boston Scientific who has manufactured the news and smallest DBS battery that last for 15 years. At the county-level, the Parkinson's community is holding a Saturday Seminar in January on *Everything You Want to Know About DBS*. With that planned, Nancy is hesitant to bring a speaker in on DBS, and does not currently have an opening this year for their representative, Anna, unless a speaker backs out. Nancy and Jim agreed that the layman's first exposure to DBS treatment should not be by a drug company.

For July's Speakers' Series, Jim Paterniti will be presenting the first 30 to 45 minutes, followed by a break, and then a panel consisting of Mike and Marta Fowler, Leila Jimenez and John Don Carlos, Joan Miller and Peter Keys, Jim Paterniti and Nancy Floodberg. It will be a round-table discussion on what a person with Parkinson can encounter when traveling. Jim and Nancy will comprise a Travel Tips List that will include the link for a card you can download from the European Parkinson's Association printed in the language of your choice saying, "*I have Parkinson's*". It will also include a list of travel tips, condensed from several articles, and combined together in one handout, with categories such as transportation, reservations, medications, etc. There will be no overhead projector presentation for Wednesday's Speakers'.

Newsletter/Calendar

For the August Newsletter, Tony will be interviewed by Dolores. Joan Miller will be interviewed by Jane Granby for the September issue. Nancy wants to get ahead for the *In Focus* articles because of the need to get the Newsletter out by the last week of the month. The last Newsletter came out after UCSD's Flying Solo meeting, which is held the 1st Wednesday of the month and noted in our newsletter calendar.

President's Report (cont'd)

The Parkinson's Hack for the August Newsletter is a three-page Excel spreadsheet of both motor and non-motor Parkinson's symptoms, created by David Bunch. It has multiple columns so that you can track your symptoms over time. Bruce will upload it to our website in 3 different formats: PDF, Excel and Numbers for Mac or Windows.

August Calendar – Tentatively date on the calendar for August 1st for the Monarch Cottage meeting, but it 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. They encountered a problem with printing the Google calendar where it showed only a little bit of the calendar. Bruce will research other calendars that could work with our Google Account.

Support Group Leader's Reports

- **Speakers' Series**
Our next Speakers' Series is on *Traveling with Parkinson's*. Jim Paterniti is the speaker. We hope to get the Leila Jimenez and John Don Carlos, Joan Miller and Peter Keys, Mike and Marta Fowler and Nancy Floodberg to participate in round-table discussion about travel problems encountered by those with Parkinson's Disease.
- **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**
Only 2 participants were at June's Oakmont meeting. Nancy will look into trying to move the meeting out of the Activity room to the Reading room. The PBPSG will remain in place for the time being while transportation by Oakmont or by FAST were discussed. Jim will co-facilitate with Nancy.
- **Do you DUOPA?**
The group will meet on July 27th. Using ZOOM will allow the Moores, now residing in New Jersey, to continue to participate in the support group.

Support Group Leader's Reports (cont'd)

- **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**

For the July meeting only four members showed up. Ron Phillips could not attend as he was having surgery for a deviated septum.

New Business

Tony

Financials

Tony reported the SDCCPSG's cash balance is \$6400.94

We will need to conduct an Audit to verify there is money in the bank. A person with good banking and accounting experience would be necessary. Will ask Peter Keys on Wednesday.

Considering a budget to purchase new books for the SCCSGP Library and \$16.00 for book Nancy wants to acquire and is listed in the August Newsletter.

Bruce

Welcome Packet and Resource Guide – Bruce will be uploading the Welcome Packet to the Parkinson's Association website so that it can be available for download.

Facebook – Bruce will be the new Social Media Director and manage our Facebook page.

August Potluck Flyer – Nancy will give Bruce the flyer in Word.doc format, Bruce will convert it to a PDF format and insert a hyperlink to our webpage.

Google Analytics – Bruce explained our website visitor pattern over the past 30 days (196 visitors; green = returning visitors, blue = new visitors) as reflected in the analytics he showed on his computer. An issue with the website: more new visitors than returning visitors were expected when we moved to our new website but now, we should have more returning visitors and fewer new visitors and that is not happening. A problem was discovered that people were being redirected to www.sdccpsg.org. It was changed to https:// to correct the problem. The search box at the top of the page has not been utilized by one single visitor in the last 30 days. Rather they are using the links to other pages instead. Webpages load in 1.39 seconds so visitors do not have to wait. Bruce will be gone this month from the 12th to the 22nd.

New Business (cont'd)

Nancy

Open Board Positions – Fundraising, Tech Support/Video, Librarian, Event Photographer.

Recorder – Tony was under the impression that we had a used Walkman recorder for Jane Granby to use. Tony and Bruce will check if they have a Walkman recorder, if not, they will look for a used one at the Thrift Stores – namely the Goodwill.

Event Photos – We need to have a member to take pictures at our events. Ron will still videotape our meetings.

Smart Agenda – Susan Howard asked if we are using a smart agenda. The agenda goes out ahead of time and is reviewed. If there is an issue it is dealt with beforehand and when you come into this meeting you are ready to go.

ZOOM Meetings – Our ZOOM account has been successfully uploaded, and trialed. It was used for the July Board meeting where three people used the ZOOM link to attend. Three screens were seen. Nancy conferred with Bruce as to how the screen would look if we invited more people to ZOOM to the meeting. Bruce said that the boxes would go down the sides and around the bottom, and the boxes would become smaller. Too many people on ZOOM would reduce the size of their boxes and it was decided to leave ZOOM with the current participants for now.

Jesse Luna's problem in accessing ZOOM for the meeting was resolved by Bruce. Bruce tried to bring several people on board with ZOOM, but they could not understand what to do, which might delay the meeting. Nancy suggested she come twenty minutes ahead of time to get ZOOM set up and to practice with it before the meeting began. Jesse suggested a script be written on how to download ZOOM, activate it, allow cookies, and log onto the meeting. Bruce said that the log-on process is different for each device (phone, computer, camera) and that we need support for people logging on. Nancy said we need a "ZOOM consultant" to do outreach to people who want to connect, get them trained, then have them log-on one at a time.

The meeting was adjourned at 11:59 am.

The next Board meeting will be held August 12, 2019 at HHSA in the University Room.

TO DO LIST

(italics = completed)

Nancy

Welcome Packet and Resource Guide – finish.

Invite – Invite Susan Howard to the next board meeting.

Name Tags – Nancy has to print and distribute them.

Librarian – Nancy is actively looking for someone to fill this position for our support group.

New Books – Purchase books by a Leanna Marie.

Speaker Series -- Nancy needs to call Dr. Kunkel's secretary again about the doctor speaking at our Speaker Series.

August Potluck Flyer – will be created by Nancy by the time Bruce returns. She will send it to Bruce in Word.doc format. Bruce will convert it to a PDF format and insert a hyperlink to our webpage.

Wesley Palms – Have heard nothing from Executive Director. Will call and let resident, Barbara Anderson, know.

Dolores

LifeWalker – need to send a thank you letter for the donation of the walkers.

Jesse

Jesse will keep a running To Do List of what people are to be doing from each meeting. Jesse will look at the past minutes and make notes.