

San Diego Central County Parkinson's Support Group
Minutes of the Monthly Meeting of the Board of Directors
September 9, 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, Dolores Cohenour, Bruce Lowe (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
Operations – Jesse Luna Hospitality
Calls – Sharon Hieserich
Timekeeper – Tony Jeske

Open Positions

Technical Support
Technical Support Jr.
Fundraising
Event Photographer

The Sixteenth 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 September 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 Minutes and the Agenda for September as written.

Nancy received the Agenda and board meeting minutes after 3:00 am from Dolores and has not had a chance to review the board minutes and moves to table the approval of the minutes until she has a chance to go through them. Nancy will send the board minutes to everyone to get their approval via email. Everyone agrees, yes.

The discussion about business cards was not on the agenda as it was an afterthought and will be added to new business under Tony.

Tony is comfortable being the Timekeeper and his name will be added as such.

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

Jodi Harrison, our Newsletter Editor and Grant Writer is in the process of moving to an apartment in San Diego. At this time, she does not have an internet and cannot log on to her computer.

Old Business Nancy Floodberg

Contact Forms

Nancy did send out a final request for the Contact to be filled out with the proper information at the beginning of September. Nancy received the names of three people whom she has never heard of before. Their names were added to the database and they do not want to be in the directory. Tony asked Nancy if there was a way to know who is new. Nancy stated you can do so by looking at the date on the very left-hand side. Tony asked what if someone wants to make a correction? Nancy responded that people cannot go to the Excel spreadsheet sheet to make corrections; they do not have access to it and must submit another form. The only thing they have access to regarding that form is either the physical form itself or through the link. The link and downloadable form will be included on our monthly newsletter email.

Nancy is having problems with the Contact Data spreadsheet online: After Date, titles do not correspond to the content beneath them. Titles are correct as you move to the right. Second, the form does not center the information and you must click at the top of the column to do so. Third, people do not enter their address correctly. They do not put the number for the address under the number column, but rather the whole address under the street column. In the column to the right of Date, Nancy is listing F (submitted a form) or a DB (off Nancy's database). Nancy is not removing people's names off her computer Parkinson's database, but feels that if you want to be recognized as part of SDCCPSG, you need to fill out a Contact Information form.

Nancy sent Tony, Dolores, Debbie J., and Bruce a link to the online Contact Information spreadsheet, so they have access to it. Tony will send Nancy a copy of the form via computer. Nancy sent Tony the link

to the Contact Information sheet so Tony can enter information sent in on the paper Contact Information form. Nancy needs to update the form, adding Mr., Mrs. She will send a separate flyer with the downloadable form and link attached stating, "SDCCPSG's Directory is coming out! If you would like to be listed, please submit your Contact Information today".

Google Calendar

Bruce and Nancy have not yet resolved the printing problem incurred with our account's Google calendar. Nancy tried to print it out, however, it showed only a few words as opposed to the entire entry, which the Word Calendar Nancy is currently using does. She has asked for Bruce's help in determining whether we can make the Google calendar work the way we want, or should continue to use Word as our calendar template.

Update on Welcome Packet and Resource Guide

Nancy still has to revise and update the Resource Guide for the Welcome Packet, and meet with Ron Phillips regarding the printing of the outer envelope. The Welcome Letter and Welcome Pamphlet are complete. Bruce has uploaded the Welcome Pamphlet to our website. The Parkinson's Association has not uploaded it to their website. Nancy asked Bruce if that was something you can resend? Bruce did not know if they would accept it or to whom it should be sent to. Nancy asked if there was an upload link on the site for unsecured information. Bruce stated that he would have to look at it to see if the pamphlet could go as an attachment and was not sure they would accept an attachment. Bruce stated that he would need an email address to forward the pamphlet so it can be uploaded to the website. Nancy state that she would contact Chris Boucher and ask who is handling the website and give Bruce the contact information.

Nancy asked if we wanted the contents of the Welcome Envelope on our website or only at our meetings. Tony, Nancy, Dolores and Bruce all said no to the additional information on the website. Bruce stated that the information is basically informational, and the pamphlet is already on the website. As we previously agreed to have labels printed out that will go on the envelopes, Nancy will see if Ron Phillips will help with the printing of those.

Old Business Tony Jeske

Audit

Tony is waiting for someone to volunteer for the audit. Nancy made a note to call Peter Keys to see if he can do the audit with Dolores. Tony stated that it can be done at the start of our new fiscal year. Nancy recalled Tony previously suggesting the addition of our P & L Statement to the minutes from each meeting. Nancy asked Tony to send her a printout before she sends out the meeting minutes for the last month, which he agreed to do. Nancy wanted to know what the audit would entail. Tony stated that he wanted 3 or 4 things to occur: first to make sure the money he claims is in the bank, is; second, if ten checks were written, then select 2 checks at random to find out if they were written to a real person; third, a print-out from QuickBooks; fourth, a Balance Sheet. We have 2 persons signing the checks and only pay by cash checks.

Old Business Bruce Lowe

Welcome Pamphlet

Bruce brought up our website on his computer and demonstrated the location of the Welcome Pamphlet by scrolling down, past the Newsletter. A downloadable PDF file is available if desired. He also stated

that he could put other items up, as well, and set it up so that it takes a minimal amount of space like the pamphlet.

President's Report **Nancy Floodberg**

Parkinson's Foundation: Aware in Care Team

Parkinson Foundation training for the Aware in Care team will be in San Diego, at the end of September, on the 26, 27th and 28. Through the Foundation, Nancy learned that Hackensack Medical Center in New Jersey is trialing a Parkinson's Hospital Policy and Procedure protocol, recently developed at the University of Rochester. Nancy expressed interest in accessing their training materials for an upcoming local pilot project. The project, with CARR (Consumer Advocates for Residential Care for the Elderly Reform), focuses on training local residential care facility administrators and their formal caregivers in how to best care for a resident with Parkinson's. The Parkinson Foundation expressed interest in partnering in the project, as well, however, at this stage involvement will be with San Diego's local Parkinson's Association.

Parkinson's Association

Tony, Jim, and Nancy Floodberg attended the monthly Support Group Leaders' meeting last Friday which provided community updates and a presentation by the Parkinson's Movement Disorder Alliance.

The Parkinson's Movement Disorder Alliance

PMDA is based in Arizona and functions as a national resource for Parkinson's communities. Their Executive Director is Sarah Jones. Sarah gave us a good visual. She said organizations like David Phinney, Parkinson Foundation, and Michael J, Fox function at the 20,000 to 30,000-foot level. While local Parkinson's organization are at ground level "on the front lines", PMDA functions at the 10-15,000-foot level, filling in the gaps between the big organizations and local communities. One of the things they are offering is local ongoing support group leader training. They offer an online lunch with the docs on a regular basis, via video conferencing to bring in physicians to talk on topics. Nancy attended an online lunch which only lasted 30 minutes. The frustrating part was that there was not enough time for the moderator to bring-up everyone's questions. Nancy went to one of their support group leaders' training sessions in Irvine with David Higgins who just attended a second one. PMDA will provide a one-day training session to support group leaders and those interested in learning more about the role here in San Diego on Friday, November 1st.

Sunset Soirée

The Soirée, the Parkinson's Association's annual fundraiser/gala, is coming up next month on the fifth of October. \$500.00 tickets are nearly sold out, however, \$250.00 tickets are still available. The event will include drinks and food tasting from multiple restaurants. Attire is casual cocktail. Nancy will have Soirée flyers to hand out at the Speakers' Series and the Breakout meetings. Discussion about SDCCPSG participants purchasing a table ensured. Nancy will follow up with those interested.

Good Start Program

The fourth and final Good Start Program will be held on the Thursday, the 24th of October, from 1:00-3:30PM at Tri-City Wellness Center in Carlsbad. Nancy Floodberg and Debbie Jordan will be there. The reason it is frequently held at this facility is because it has excellent parking and venue access. Chris Buscher received a call from resident Barbara Anderson at Wesley Palms offering their facility. The venue

may present parking issues, however, at Chris's request, Nancy will follow up.

Empowerment Day

Empowerment Day will be held on Friday, November 15th. Debbie Jordan and Nancy Floodberg will staff our support group table. Nancy will also have an Aware in Care table. There will also be a support table staffed by members of the San Diego Access and Crisis Line, as well as a UCSD social worker. The Crisis Line number is now listed in our monthly newsletter.

SDCCPSG

- **September Breakout Meeting**

Nancy Floodberg will not be here for the meeting on Monday, October 23rd. Jim Paterniti has offered to facilitate.

- **Open Positions**

The fundraising and tech support positions are open. People who might fit the positions are CARR co-founder, Chris Murphy's husband, Carl, should he choose to participate in our support group in the future, and Lee Carver and, his wife, Susan Cahill, who are currently out of town, but returning later this fall.

- **ZOOM Consulting and Script**

Nancy asked Bruce if they could brainstorm together to develop a script for Zoom so those who are unable to attend a breakout meeting in person can do so from home. Once in place, Nancy will reach out to the Barfells and the Hoveys, who previously participated, however, no longer live in San Diego, to see if they want to join us via ZOOM.

- **Librarian**

Deborah Jordan has filled the Librarian's position. Nancy does not have any books to donate at the present time.

- **Videographer**

Ron Phillips will be videotaping the Speaker's Series on Wednesday and Kagen will be his assistant.

- **Smart Agenda**

Smart Agenda is on hold for now because Susan Howard will be traveling out of the country.

- **Speakers' Series**

Dates for this Fall's Speaker's Series are Oct 9th and Nov 13th. Since Dr. Paceto (sleep specialist) is recovering from surgery and Dr. Kunkel (gastroenterologist) has not gotten back to Nancy regarding his availability, David Chong, Executive Director of Coast Care Partners, will be September's speaker. His topic will be Navigating the Senior Care Landscape. Coast Care won the contract, with Southern Caregivers' Resource Center, to oversee the county's million-dollar pilot project, Be Well Respite, designed to provide support and respite care to people living with dementia. He and his team will be talking about this, the VA's Aid and Assistance program, as

well as cannabis and its many healthcare uses. Accessing Mobile Medical Services will be the October 9th topic if neither physician is available.

- **Christmas Party, Wednesday, December 11th.**

The Christmas party will be listed in in the newsletter. Nancy reserved the Tremble Clefs last December for our holiday party this year and will confirm. Deanna Hastings has stepped away from her role as the accompanist with the Tremble Clefs and they are in transition in regard to that.

Newsletter/Calendar

Newsletter reporter, Jane Granby, has been trying to interview Joan Miller for the October issue, however, she and her husband, Peter Keys, have been out of town. Nancy's daughter, Tessa La Pointe, raised money by selling boxes of cards on Facebook which she is donating to SDCCPSG in honor of her father, John Floodberg. Tessa will come to our September Speakers' Series to present the money to Tony. Dolores will interview Tessa for the October In-Focus newsletter article.

Support Group Leader's Reports

- **Speakers' Series**

The speaker for the September's series is going to be David Chong from Coast Care Partners. They are one of the top 10 to 15 care agencies in San Diego. The VA/UCSD will also present as their research projects have changed or are being started.

- **PLPSG**

Lee Carver and Susan Cahill, as well as Bill and Sue Munzer are new and coming attending our group.

- **La Jolla: Monarch Cottage**

Jim and Nancy met with Monarch Cottage Sales Counselor, Phil Mikelatos, and decided that prior to starting a potential support group, as requested by Monarch Cottage, a community presentation on Parkinson's would be appropriate to determine both need and interest. La Jolla has a fair number of persons with Parkinson's, including 1/3 of the 26 residents at Monarch, who do not appear to be reaching out and accessing services or a movement disorder specialist. Speakers (Chris Buscher, Dr. Nelson Hwynn, Nancy Floodberg & Jim Paterniti) have been identified, however, the venue has not been determined. In the interim, Nancy was informed that Phil is no longer with the facility. Their Marketing Director, Bobbi Thomas, has stepped in and, if unable to identify a venue available on the dates proposed, will postpone the presentation until the new year.

- **PBPSG**

Attendance at our support group at the residential community, Oakmont of Pacific Beach, has been low and inconsistent. As a result, a consistent,

core group has not evolved. Nancy is questioning whether the group is a good use of her time, however, will continue the group for now and see what happens.

- **Do you DUOPA?**

The Duopa support group will be meeting on Saturday, September 28th. Attendance has been consistent, including the pharmaceutical rep and Zoom participants, Mike and Cindy Moore, in New Jersey. Interest in our group was expressed during an Aware in Care video conference by two users in other areas of the country. Nancy's contact information was shared with them and they reached out via email, however, neither has responded to Nancy's reply. In theory, they, too, could participate via Zoom.

- **Flying Solo**

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

- **Veteran's**

The Veteran's group has not had many in attendance recently and support group leader, Ron Phillips is considering closing it and combining with the Pt. Loma group. Nancy informed Ron that the September Speakers' Series will be addressing the Veteran's Aid and Attendance program and invited him to share the information with his group participants.

New Business

Tony

Financial

Our balance is \$7,736.00. We did not get enough activity on Amazon to qualify for a donation this month. The Network for Good gave us a \$36.00 donation. For the second time we received from Your Cause, the trustee for the Wells Fargo community support campaign, a donation of \$25.00. The money came in through Skype and Tony is sending an acknowledgement. Other than that, we received small donations of \$5, \$10, \$20 dollars We have not heard from the state about our sales tax exemption.

Directory

Tony is working on it, using Access as the platform.

Stationary

Tony sent Nancy and Dolores a copy of the revised stationary.

Business Cards

The need for a general support group business card was discussed. Tony share the concept, AIDA, in developing an eye-catching card.

Debbie Jordan

Contact Information Forms

Debbie volunteered to make calls regarding missing information on received Contact Information forms, however, may not have the most current contact list. Tony stated that most of the people were on the list he gave Debbie. It was agreed we will wait until Tony has the directory information entered to let determine what is missing and the need for follow up by Debbie.

Social Committee Assets

Debbie is taking an inventory of the assets and will give Nancy a copy. Debbie does not have any of the Christmas assets. Debbie Stubbie may have them.

Library

Debbie is tracking the books that are still out. Debbie needs the address for the person who has the book *Brainstorms*, and Michael Moore's address. Since Debbie Jordan, Debbie Stubbe, and Nancy Floodberg will not be at the Wednesday night meeting, the books will not be on display. Nancy had purchased books that she will donate to the library: *Don't Rain on My Parade*, *Living with Dementia*, and *The Long Moment*, which is about caring for people with dementia. Debbie does not think that *Parkinson's for Dummies* will be returned. Nancy said that Jim Paterniti has a newer copy that he will donate. Nancy stated that if *Brainstorms* is not returned by AnnD, we need to replace it. Debbie will send Bruce a list of the Library's books, and steps on how to check out a book from the Library.

Stamps

Debbie has not used any of the stamps from the roll of 1000 stamps.

Cards

Debbie suggested we keep a log of the cards we are sending out, including any correspondence.

Bruce

Library

Bruce suggest we put something on the website about the Library and how to contact the Librarian. Bruce will receive a list of the available books from Debbie, and how to check out a book from it and put it on the website under Resources.

Google Analytics

Bruce has to go in and find out why SDCCPSG's website analytics disappeared and what happened. Bruce's normal analytics dropped off and Google does not know who we are. Apparently, there was a protocol to follow. Bruce has a back-up called Clicky, which showed that we had more than 20 visitors. Bruce said that he thought we were ok with Google and had shut off the tracking device which does not cover everything. It did give us an idea of the number one thing people come to the website for, the calendar, then support group information, then the Speaker Series, and then the remaining content. We had fewer people visit, but it was not a good snapshot. Bruce will work on the information and will send it to us via email.

Facebook

Although Facebook is everywhere, it is a vessel for things that Bruce cannot support. He killed his account and the Parkinson's group page since they were attached. The account is no longer up and running. If anyone in the group has the skill and wants to work on it, so be it. If in the future we were to be on Facebook again, we would want a page and not a group. If we did a page, and the group membership became large and wanted to talk about what they wanted to, then they could create a group. AnnD Canavan created a group page and she was the only one who contributed to it. Do we want people to find out about us on Facebook versus the website with more information and resources? Everyone agreed the website is where we want to direct people.

Dolores

Thank You Notes

Dolores received the stationary from Nancy to create a thank-you note for ProtoStar's walker donations, and got a thank-you card for Tessa. Dolores spoke to Nancy about a gift card for Tessa and Nancy said she would bring it up at the next meeting.

Nancy

Newsletter

Possible Parkinson's Hacks. Patsy got a mouth infection from using Imbrija. It is mentioned lightly in the pamphlet but was not mentioned at the presentation. In the newsletter, we need to mention that when you use it, you must immediately rinse your mouth with water and mouthwash in order to reduce the chance of a mouth infection that could result from a build-up of the powder.

It was also mention that you do not need to come off your medications when you must undergo anesthesia. The anesthesia doctor can alter it by pulling out certain drugs so you can stay on your medications. Dolores brought that it would be a good topic for the Speakers' Series, a presentation by persons who have undergone surgeries and what to do to be prepared. Debbie Jordan has an article about people with Parkinson's undergoing surgery.

Another possible Hack to include: if the JPEG of the Duopa pump comes undone, and is pushed back in, an X-ray is needed to confirm that it is in the right in front of the jejunum to offload dopamine. Mobile Medical Services can come to you home for the X-ray and it is covered by Medicare.

Business Cards

We need a generic business card that grabs your 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 will send Dolores copies of UCSD’s and North County’s business cards. Tony suggested the AIDA principles.

Cards Purchased from the Support Group Fundraiser

Nancy will provide Tony with a receipt for reimbursement of \$30.00 that says “Dolores ask me to purchase the card for Debbie Jordan to use.

Meeting Rooms

Nancy will publicize our meeting with the start time as 9:45 a.m. so that everything will be set up and ready to go by 10:00 a.m. and we will be out of the room by noon, 12:00 p.m.

The meeting was adjourned at 11:58 am.

The next board meeting will be Monday, October 14th, at HHSA in the San Diego Room.