CurePSP, Inc.

Minutes of the Board of Directors
July 9, 2016

The Board of Directors of CurePSP, Inc., met in Las Vegas, Nevada on July 9, 2016.

Board members in attendance were: Bill McFarland, Chair; Everett Cook, Vice-Chair; Mike Dixon, Secretary; John Burhoe, Chair Emeritus; Paul Freeman; Jeff Friedman, MD, PhD; Stephen Goldman; Ileen McFarland. George Jankiewicz, Treasurer, attended by video conference.

CurePSP staff in attendance was: Dave Kemp, President; Alex Klein, Vice President-Scientific Affairs; Russell Gardner, General Counsel. Trish Caruana, Executive Vice President, attended by video conference;

The meeting was called to order by Mr. McFarland.

A moment of silence was observed.

The minutes of the previous Board meeting, having been earlier distributed to the Board, were approved by motion.

Review of Action Items: Mr. McFarland reviewed the status of matters identified as Action Items at the February Board meeting:

Action Item: Committee meeting summaries are to be forwarded to Ms. Speca within 30 days of the meeting; Ms. Speca will distribute meeting summaries to all Board members.

Status: Mr. McFarland reported that minutes of the Board and committee meetings will be posted on the password-protected portion of the CurePSP website. Mr. Kemp will designate a member of the staff to produce minutes of the several committees; Mr. Gardner will continue to record the proceedings of the Board and Executive Committee.

Action Item: Mr. McFarland directed that a one-page “snapshot” of our financial condition be distributed on a monthly schedule, after Finance Committee review, to the Board.

Status: Mr. McFarland reported that a snapshot of the organization’s financial standing will be provided on a monthly basis to the full Board.

Action Item: Mr. McFarland asks Drs. Klein, Golbe and Friedman to confer with the Scientific Advisory Board as to whether CTE might be included within CurePSP’s mission statement. Mr. McFarland requested that a recommendation be presented at the July Board meeting.
Status: Drs. Klein and Friedman recommended that the Board authorize CurePSP to expand its mission statement to include disorders that share common pathology with PSP, including CTE. It was further recommended that the Board authorize the appointment of an expert in the CTE field to the Scientific Advisory Board. Discussion.

MOTION (Mr. Burhoe): To expand our focus to include other Prime of Life disorders that share pathologic and ideational factors with PSP. PASSED-unanimous.

Action Item (new): Drs. Klein and Friedman were requested to identify a candidate with expertise in the field of CTE for addition to the Scientific Advisory Board.

Action Item: Board and Leadership Committee to increase efforts to recruit substantial givers.

Status: Discussion was deferred until later in the meeting.

Action Item: Mr. Kemp is to present a specific plan for relocation to New York at the March 17 Executive Committee meeting.

Status: This item has been completed.

Fall Board Meeting: Mr. McFarland reported that the Fall Board meeting will be held on October 29 in conjunction with the Scientific Symposium. The meeting and Symposium will be held at the Hyatt Regency, Jersey City, New Jersey.

Spring 2017 Board Meeting: Discussion of whether to hold a Board meeting in a locale more convenient to the West Coast. Discussion of holding the spring 2017 Board meeting in Phoenix, Arizona, in conjunction with a family conference scheduled for mid-March.

MOTION (Mr. Burhoe): To hold the spring 2017 Board meeting in Phoenix, Arizona, on March 17 or 19, as may be determined. PASSED-unanimous.

Action Item: Mr. McFarland will poll Board members to determine a preference for either March 17 or March 19 Board meeting.

Departing Board Members: The Board expressed its thanks for the dedicated services of departing Board members Yvette Bordelon, Heather Cianci, Burt Benjamin, and Paul Freeman. Mr. McFarland reported that Mr. Freeman will continue to serve on the Finance Committee.

Election of Board Members: Their terms of office having expired, it was recommended that Amy Branch, Mike Dixon, Larry Golbe, Steve Goldman, Bill McFarland, Ileen McFarland, and Adam Murphy be re-elected to the Board. The recommendation was accepted and Amy Branch, Mike Dixon, Larry Golbe, Steve Goldman, Bill McFarland, Ileen McFarland, and Adam Murphy were re-nominated. Yvette Bordelon, MD, Burt
Benjamin, MD, and Heather Cianci, whose terms have expired, chose not to stand for reelection to another term. Paul Freemen resigned from the Board before the expiration of his term due to heavy work and family demands on his time.

MOTION (Mr. Burhoe): That Amy Branch, Mike Dixon, Larry Golbe, Steve Goldman, Bill McFarland, Ileen McFarland, and Adam Murphy are elected to a full term as members of the Board. PASSED – unanimous.

Mr. McFarland will review committee assignments, with a view toward having an early meeting of the Compensation Committee. Mr. Goldman suggested that Board members provide biographical information for posting on the website.

Action Item: Board members and members of the Scientific Advisory Board are to send a brief biographical statement and photo to Mr. Kemp.

Conflict of Interest: Mr. Gardner spoke of the need to provide annual disclosures of potential conflicts, or the acknowledgement that no such conflict exists, to the General Counsel.

President’s Report: Mr. Kemp reviewed and distributed several items of promotional literature, and encouraged Board members to distribute to friends, colleagues and potential donors. Mr. Kemp spoke of CurePSP 2.0, an effort to build a for-profit culture, which Mr. Kemp defined as built around customer service and market focus.

Mr. Kemp reviewed the status of the New York office, including updating technology infrastructure. A brief video of the New York office, produced by Mr. Metherall, was shown to great approval. Mr. Kemp also reviewed his efforts to build a Next Gen Team. Finance, under the day-to-day direction of Diane Seegull, will remain in Baltimore, as will Ms. Caruana temporarily (her plan to move to NY having been delayed for the time being by health issues). Ms. Caruana’s duties will be split more or less evenly between CurePSP and PEP. With CurePSP, Ms. Caruana will support Ms. McFarland’s activities. Ms. Caruana is currently looking to fill an account executive position for PEP.

Mr. Kemp reviewed activities with respect to its intellectual property. Our brand is “Prime of Life,” with the message that PSP is the key to unlock the secrets of brain disease. The phrase “Because Hope Matters” is in the process of securing trademark protection. A new website will be launched in late summer. The newsletter and other publicity will be produced in-house, and will be more focused on supporting local events.

Mr. Kemp reviewed fund raising activities. With respect to the Annual Fund, there will be an emphasis on recovering lapsed donors and looking for opportunity to grow the donor base. With respect to other fund raising activities, the current emphasis is on understanding the database and how we can use it more effectively. Mr. Kemp urged Board members to annually attend at least one fund raising event; he will coordinate.
The Raiser’s Edge Dashboard was demonstrated by Mr. Kemp. Board members will be provided access to Raiser’s Edge, and are encouraged to use it in their fund raising efforts.

**Action Item:** Mr. Kemp is to review security of our fund raising activities.

**Finance Committee:** Draft budget projections were distributed. Mr. Jankiewicz reported that PEP’s finances are in a state of flux, and its projected revenue will not be included in CurePSP’s FY 2017 budget. He remarked that PEP is very uncertain. Preparation for the FY 2017 budget for CurePSP is on-going, using a zero-base model. It is the Committee’s perception that CurePSP’s past performance is not a guide to today’s CurePSP. It was noted that the Finance Committee has not approved a budget. Rather, the proposed budget is a management budget, with the caveat that the Committee is to closely monitor performance against the budget, looking hard at basic milestones on a quarterly basis. If revenue is there, expenditures will follow.

Mr. Kemp expressed his thanks to Ms. Seegull for developing solid numbers for the budget. He explained how revenue/expense projections were made.

Lengthy discussion of the proposed budget followed, including review of payroll projections, line items, and research funding. There was discussion of the need to follow up on performance of researchers against expectations.

Mr. Freeman noted that the Finance Committee did not recommend the proposed budget because of concerns over income projections. He remarked that this is a management budget, which the Board has to own the budget. He urged a serious look at PEP.

**MOTION (Mr. Burhoe):** To accept the proposed budget – PASSED unanimous.

It was proposed that Finance Committee proceedings be available to all Board members through video conference.

Mr. McFarland read Ms. Cianci’s resignation email to the Board. Discussion followed, observing that Ms. Cianci has made significant contributions in the past and those efforts are noted and appreciated. Mr. McFarland will contact her and encourage her to remain active in a non-Board member role.

Dr. Klein and Ms. Caruana reported on CurePSP’s activities at the Berlin conference on movement disorders. It was viewed as a good meeting with good contacts. It also offered Ms. Caruana the opportunity to make pharma contacts with respect to PEP’s activities.

**Physician Education and Clinician Advisory Committees:** Mr. McFarland reported that we need to add physician to the Board. Mr. McFarland announced that the Medical Professional Committee formerly chaired by Ms. Cianci was dissolved for lack of interest.
PEP: Ms. Caruana reported that PEP is changing its focus from only recruitment to working with clients throughout the life cycle of the clinical trial. Discussion of trends in the pharma industry. Ms. Caruana reports that PEP has established trust, level of service with pharma clients. PEP offers needed service. Ms. Caruana plans to continue working closely with pharma. Ms. Caruana reports work in progress is valued at $564,000.

Ms. Caruana reviewed lessons learned and responses to those lessons.

Advocacy/Government Affairs Committee: Dr. Goldman spoke of how Board members may influence government funding agencies to fund research into PSP and related diseases. Discussion. Mr. McFarland appointed Dr. Goldman as Chair of the Advocacy Committee, with Dr. Friedman, Mr. McFarland and Ms. McFarland as members.

Major Gifts Committee: The Committee’s report was submitted in writing by Ms. Branch. That report is attached and incorporated in these Minutes.

Research Committee/SAB: Dr. Klein reported there were five applications for funding. The SAB recommends funding of the following grant applications:

- Oxidative damage and gene deregulation in PSP and related disorders.
  Principle Investigator: Sanchez-Contreras
  Requested funding: $92,501 (one year)

- Evaluation of STX6 silencing on the novel AAV-based mouse model.
  Principle Investigator: Ikezu
  Requested funding: $100,000 (two years)

Discussion with regard to affordability of proposed grants in light of budget uncertainties.

MOTION (Dr. Friedman): To accept SAB’s recommendations and provide the requested funding, subject to CFO approval that sufficient resources are available to support the requests. If only one application can be funded, priority shall go to the Ikezu application. PASSED-unanimous.

Discussion of how funding may be secured for the requested grants.

Review of the URSO Fellowships, as follows, and requested the Board approve the applications:

- Sleep study ($3,000). This study is not progressing and funding may be withdrawn.
- Development of PSP mouse model ($3,000). This study is progressing in a satisfactory manner.
ADDF: Matching funding of up to $100,000. A memorandum of understanding is in progress.

Dr. Klein recommends that we join with the FTD disorders registry. He reports that this is a 501(c)(3) entity, and we will have a representative on the Management Committee.

MOTION (Dr. Friedman): Dr. Klein and Mr. Kemp are authorized to negotiate partnership with Registry, and to thereafter report to the Board through the Executive Committee. PASSED-unanimous.

Review of brain bank. The brain bank has requested an annual grant of $98,000. We currently fund at a $66,000 level. Tau Consortium offers to contribute $100,000 to brain bank if CurePSP maintains current funding level.

Centers of Excellence are developing well. Eligibility criteria are done, scoring sheet is a work in progress, and master plan is under way through Drs. Bluett and Golbe. CurePSP has made not funding commitment, although CurePSP will fund marketing and related activities. Expect to launch CoE in 2017.

Discussion about 2017 research symposium.

Dr. Klein provided an update of activities in Australia. He noted that CurePSP-Canada would like to host a Board meeting.

Patient and Carepartner Advocacy Committee: Ms. McFarland reported that the Committee has developed a mission statement. She further reported on encouraging local support groups to engage in advocacy on national level. Ms. McFarland urged Board members to attend family conferences and other meetings, noting that participation can be by Skype as well as in person.

The next regular meeting of the Board of Directors will be October 28 in Jersey City, New Jersey.

There being no further business, the meeting was adjourned by motion.

Respectfully submitted,

Russell Gardner
General Counsel