



**RESEARCH PROGRAM
POLICIES AND PROCEDURES
APPROVED BY THE BOARD OF DIRECTORS ON MARCH 1, 2008**

CUREPSP
SOCIETY FOR PROGRESSIVE SUPRANUCLEAR PALSY
Executive Plaza III
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VISION

Cure and prevent PSP and CBD

MISSION STATEMENT

Increase awareness of progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD), fund research toward a cure and prevention, educate health professionals, and provide support, information and hope for persons and families with PSP and CBD.

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1. OVERVIEW OF THE CUREPSP RESEARCH PROGRAM

The Society for Progressive Supranuclear Palsy (CurePSP) Research Program supports and promotes research that can advance the understanding and treatment of progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD). CurePSP's Research Program has three components:

INVESTIGATOR-INITIATED RESEARCH

CurePSP promotes research that helps generate an integrated picture of PSP and CBD at the molecular, cellular, and clinical levels. CurePSP may offer grants of up to \$100,000 per year for three years, the award maximum and duration varying per submission cycle.

CLINICAL TRIALS

In an effort to encourage investigators to plan and execute PSP/CBD clinical trials, CurePSP earmarks money for investigator-initiated clinical trials.

CUREPSP- INITIATED RESEARCH

CurePSP may encourage independent investigators to submit applications for its internally initiated research funding mechanism by issuing a request for applications (RFA).

CurePSP is particularly interested in research that will help us:

1. Understand the role of the tau gene and other genes in PSP and CBD.
2. Understand the role of tau protein processing in PSP and CBD.
3. Understand cellular energy metabolism and oxidative stress perturbations in PSP and CBD.
4. Understand environmental factors that influence the development or course of PSP and CBD.
5. Understand the series of changes brain cells pass through in PSP and CBD as they progress from healthy neurons to dysfunctional neurons.
6. Characterize the natural history of PSP and CBD in order to develop outcome measures for clinical trials.
7. Develop animal models of PSP and CBD.
8. Develop tools and disease markers for early diagnosis of PSP and CBD and for assessment of treatment.
9. Develop treatments that improve the symptoms of persons with PSP and CBD.
10. Develop interventions to arrest the progression of PSP and CBD and restore lost function.

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2. SCIENTIFIC ADVISORY BOARD (SAB) AND THE PEER REVIEW PROCESS OF APPLICATIONS

All proposals are subjected to peer review. CurePSP's Director of Research & Clinical Affairs distributes the applications to the Scientific Advisory Board (SAB). The SAB functions as the Peer Review Committee. Each application is assigned to at least three committee members for initial review.

The SAB evaluates applications based on some or all of the following criteria: (a) the scientific merit, originality, and feasibility of the application; (b) the relevance of the work to PSP; (c) the qualifications, experience and productivity of the applicant and members of the investigative team; and (d) the facilities and resources available.

Members of the SAB review the applications and submit numerical scores to the SAB chair, who tabulates them. At its semiannual meeting, the SAB discusses the applications, their scores and their budgets and formulates a list of funding recommendations. The SAB chair forwards these recommendations to a Research Committee designated by the Board of Directors. The Research Committee then considers these recommendations in the light of CurePSP's mission and budget. After considering the recommendations of the SAB and Research Committee, the Board of Directors determines and approves which grants will be funded. The President-CEO is then authorized to distribute funds. All CurePSP research grants and awards are made by the President and Chief Executive Officer under the authority and on behalf of CurePSP's Board of Directors.

The principal investigator is responsible and accountable for the overall conduct of the project.

CurePSP does not discriminate on the basis of country of origin, race, creed, religious belief, or sexual orientation. Researchers who receive funding from CurePSP may be required to provide certification that the institutions in which they are employed do not engage in any discriminatory activities.

3. APPLICATION DEADLINES

Application deadlines for the Spring Cycle are usually April 1st. For the Fall Cycle the deadline is usually October 1st. When these dates fall on a weekend or holiday, applications will be accepted through the next business day.

4. NOTIFICATION OF APPLICATION RECEIPT AND REVIEW

Approximately one month after receipt of the application, the applicant will receive an email acknowledgment providing an application number.

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For administrative questions, applicants may call the Assistant Director, Finance and Research Services at any time during the review cycle. For more in-depth questions concerning the review process, the Director of Research & Clinical Affairs can also provide information and feedback. Applicants considering resubmission are strongly encouraged to contact the Director of Research & Clinical Affairs well in advance of the next deadline.

5. GRANT PAYMENTS

1- Year Grants:

50% payable at start of project, 25% payable after satisfactory 6-month progress report, and 25% payable after satisfactory final report.

2- Year Grants:

50% payable at start of project, 25% payable after satisfactory 12-month progress report, and 25% payable after satisfactory final report.

3- Year Grants:

40% payable at start of project, 20% payable after satisfactory 12-month progress report, 20% payable after satisfactory 24-month progress report, and 20% payable after satisfactory final report.

CurePSP will consider exceptions to these schedules on request from the PI for projects that require a disproportionate fraction of funding at one point in the term of the grant.

Grant payments will be made to the sponsoring institution and are mailed to the address indicated on the grant application form. Acknowledgment of payment by the sponsoring institution is not required. Personnel compensated in whole or in part with funds from CurePSP are not considered employees of CurePSP. Institutions are responsible for issuing the appropriate IRS tax filings for all individuals receiving compensation from CurePSP grants and are responsible for withholding and paying all required federal, state, and local payroll taxes with regard to such compensation. Thus, these and any other tax consequences are the responsibility of the individual recipient and the sponsoring institution. CurePSP advises all grant and award recipients to consult a tax advisor regarding the status of their awards.

6. ANNUAL AND FINAL PROGRESS REPORTS

Progress reports must be written for a technical audience. They are to be submitted per the following schedule for 1-year, 2-year, and 3-year grants.

1- Year Grants: 6-month progress report and final report after project completion. Total 2 reports.

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2- Year Grants: 12-month progress report and final report after project completion. Total 2 reports.

3- Year Grants: 12-month progress report, 24-month progress report, and final report after project completion. Total 3 reports.

Reports must be submitted within 60 days of their due dates. Requests for extensions of progress report due dates will be considered if submitted in writing before that point. CurePSP will provide reminders and may terminate the grant without further payment for failure to submit progress reports on time. In such cases, CurePSP may request from the institution an accounting of funds expended to date and may require the return of any unspent funds.

Final reports should cover the entire grant period. In the event a grant has been extended without additional funds, the final report is not due until the official termination date of the grant. If the grant is terminated early, a final report must be completed within 60 days of the termination date.

Final reports must include, on a separate page, a non-technical-language abstract of 200-300 words for publication in CurePSP's newsletter and other informational materials. This abstract may be edited by CurePSP before publication to improve readability by a general audience.

7. PUBLICATIONS, SYMPOSIA, AND OTHER RESEARCH COMMUNICATIONS

Publications resulting from research or training activities supported by CurePSP must contain the following acknowledgment: "Supported by Grant # (insert grant number) from CurePSP – Society for Progressive Supranuclear Palsy." CurePSP's support should also be acknowledged by the grantee and by the institution in all public communication of work resulting from this grant, including scientific abstracts (where permitted), posters at scientific meetings, press releases or other media communications, and Internet-based communications.

Annual Research Symposium: Principal Investigators (PI) agree to present their results at CurePSP's annual research symposium, usually held immediately after the meeting of the Society for Neuroscience and in the same city. Unless adequate funds from other sources are available, travel and lodging expenses for this meeting must be included in the project proposal budget. The presentation will occur at the first annual symposium occurring after the expiration of the term of the grant.

8. FINANCIAL RECORDS AND REPORTS

Annual financial reports may be requested at the discretion of CurePSP. Signatures of the principal investigator and the institution's financial officer are required on such reports. Any unexpended funds must be returned to CurePSP.

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CurePSP is not responsible for expenditures made prior to the start date of the grant, for commitments against a grant not paid within 60 days following the expiration date, or any expenditure that exceeds the total amount of the award.

9. INSTITUTIONAL EXPENDITURES

CurePSP research grants are not designed to cover the total cost of the research proposed nor the principal investigator's entire compensation. The grantee's institution is expected to provide the required physical facilities and administrative services normally available in a research institution.

CurePSP's research grants do not provide money for facilities and administration costs ("indirect costs") or funds for such items as:

- Secretarial/administrative salaries
- Books and periodicals
- Membership dues
- Office and laboratory furniture
- Office equipment and supplies
- Rental of office or laboratory space
- Recruiting and relocation expenses
- Personal services
- Construction, renovation, or maintenance of buildings or laboratories

CurePSP may request an accounting of grant funds expenditures from the institution at any time during or after the term of the grant or its extension(s).

10. OWNERSHIP OF EQUIPMENT

Equipment purchased under CurePSP research grants or extensions thereof is for the use of the principal investigator and collaborators. Title of such equipment shall be vested in the grantee institution. In the event that CurePSP authorizes the transfer of a grant to another institution, equipment necessary for continuation of the research project purchased with the grant funds may be transferred to the new institution. Title to such equipment shall be vested in the new institution.

11. NO-COST EXTENSION OF TERM OF GRANT

CurePSP will consider two extensions of up to 6 months each in the term of a grant without additional funds beyond what was originally awarded ("no-cost extensions"). A request for extension should not exceed two pages, and must describe the progress to date and the reason for the delay. The grant will expire 60 days after the grant's original termination date if the grantee has submitted neither a final progress report nor a request for a no-cost extension, or if

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one extension has been granted and the grantee submits neither a final report nor a request for a second extension.

The grant's final payment will not be made if:

- 1) a request for a no-cost extension is rejected, or
- 2) a final progress report is not submitted to CurePSP within 60 days of the expiration of the grant and any extensions, or
- 3) the final progress report is considered by CurePSP to be unsatisfactory for any reason.

12. TERMINATION AND/OR CANCELLATION OF GRANT

In the event a grant is canceled by CurePSP or terminated before the end of its original term, no further funds will be disbursed and all unexpended funds previously disbursed must be returned. CurePSP cannot assume responsibility for expenditures in excess of payments already made to the grantee institution prior to the effective date of cancellation, and all unexpended funds must be returned to CurePSP.

13. CHANGE OF INSTITUTION

Recipients of Research Grants may transfer their grant from one institution to another only after receiving written approval from CurePSP. Grant recipients must notify CurePSP to request a transfer as soon as they are notified that they will be changing institutions. Prior to a transfer, CurePSP must receive the following: The request for transfer in writing from the new institution, in the form of a revised front page of the grant; A statement from an administrative official at the original institution relinquishing the grant; The Report of Expenditures from the original institution together with a check for any unexpended funds. Payments to the new institution will not be initiated until a final accounting and a check for any unexpended funds have been received from the original institution and the transfer has been approved by CurePSP. This final financial report must be submitted within 60 days of the date the transfer was requested.

14. GRANT APPLICATION INSTRUCTIONS

INTRODUCTION

CurePSP does not assume responsibility for the conduct of the activities that the grant supports or the acts of the grant recipient as both are under the direction and control of the grantee institution and subject to the institution's medical and scientific policies. Grantee institutions must safeguard the rights and welfare of individuals who participate as subjects in research activities by reviewing proposed activities through an Institutional Review Board (IRB), as specified by the National Institutes of Health Office for Human Research Protections, US Department of Health and Human Services. Furthermore, grantee institutions must adhere to DHHS guidelines regarding financial conflicts of interest, recombinant DNA, research misconduct, and vertebrate animals. These policies apply to applicants and applicant institutions

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as well. An application for a grant must bear the signature of the official authorized to sign for the institution. Signature of the department head is also expected. Additional signatures are at the discretion of the institution.

WHAT TO SUBMIT

Please submit research grants as follows: A single pdf file on a CD with the file name being the applicant's last name then first name; a hard copy with original signatures; and one printed hard copy.

The first page of the application hard copies must contain:

- The full information requested for the Cover Page (see below)
- The signatures of the Investigator, Institutional Signing Official, and the Department Chair.

The first page of the PDF must contain:

- The full information requested for the Cover Page (see below).
- Inclusion of signatures on the first page of the PDF is preferred, but is not mandatory.

The electronic and paper applications must be submitted and received by CurePSP's office by close of business (5:00 PM Eastern time) on the specified deadline date. If the deadline date falls on a weekend or holiday, applications will be accepted through the following business day.

FORMATTING THE APPLICATION

For ease of review, applicants should adhere to the following instructions in completing the proposal sections that make up the application. Failure to observe the size specifications and/or page limits may result in the return of the application without review.

Headers: Please insert your name in a header for each section of the application (not required for the cover page).

Type size: Use 11 point Times New Roman or Arial as the minimum font size for the text of the application. A 10-point Times New Roman or 9-point Arial font type may be used for figures, legends, and tables.

Single-spaced text is acceptable. Paragraphs must be delimited by an extra line space or an indentation.

Margins: The margins of your text should be at least 1 inch all around.

COVER PAGE, Page 1.

Applicant Name
Position Title
Institution Name
Proposal Title (Limit to 75 characters)
Duration of Grant

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Total Amount Requested

Department Chair

Name

Signature

Date

Contact Information (include email & fax)

Institutional Official

Name

Signature

Date

Contact Information (include email & fax)

Applicant

Name

Signature

Date

Contact information (include email & fax)

ABSTRACT PAGE

On the second page of the application, right after the cover page, provide a page that contains both a non-technical abstract for general audiences (200 to 300 words) and a structured technical abstract (200 to 300 words). The non-technical abstract should retain the same organization as the technical abstract but scientific terms should be avoided or, when necessary, clearly defined. In order to conform to the word limit, methodological details can be omitted or abbreviated. The last sentence or two of the non-technical abstract should describe how the work would advance our knowledge of PSP/CBD.

Structured Technical Abstract: The structured technical abstract is a summary of the proposed research or scholarly project for general scientific audiences. It should not exceed 300 words in length. It should provide a clear, concise overview of the proposed work by addressing the following points:

- **Background:** Provide a brief statement of the ideas and reasoning behind the proposed work.
- **Objective and hypothesis:** State the objectives and hypothesis to be tested. Cite evidence or provide a rationale that supports it.
- **Specific aims:** Concisely state the specific aims of the study.
- **Study design:** Briefly describe the study design, emphasizing those elements you consider most relevant to assignment of the proposal for peer review.
- **PSP/CBD relevance:** Provide a brief statement explaining the potential relevance to PSP/CBD. If this application is funded, this description will become public information. Therefore, do not include proprietary or confidential information.

BUDGET PAGE

After the abstracts, please provide a project budget. When preparing the budget, please note the following:

- The maximum allowable for the PI salary is 15% of full-time effort.

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- No support for indirect costs or institutional overhead is permitted.
- The maximum allowable for durable equipment is \$8,000.
- Unless travel funds are available from other sources, the budget must include the cost of travel and lodging for the PI to attend one of CurePSP's research symposia (the one soonest after the expiration date of the grant) to present the final results of the work. These are ordinarily held in the same city as the Society for Neuroscience meeting.

The Project Budget should be organized as follows:

Personnel: The names and positions of all personnel must be individually listed and the percentage of time to be devoted to the project by each person should be noted, even when salary is not requested. If an individual who will perform a part of the proposed work has not yet been selected, please list as "vacancy." Provide the dollar amount of direct salary support, plus the dollar amount that will be applied towards fringe benefits.

PLEASE NOTE: Include letters of intent to collaborate or consult in the Appendix. Details of contractual arrangements with collaborators or consultants should also be clearly noted in the Budget section of the application. We define **collaborators** as individuals who will participate actively in the design and execution of the studies, and **consultants** as individuals who will provide any combination of advice, guidance, and reagents without "hands on" involvement in the project.

Permanent Equipment: Defined as all items costing over \$500 with a useful life of 2 or more years. List separately and justify the need for each item of equipment.

Supplies: Group into major categories (glassware, chemicals, radioisotopes, survey materials, animals).

Miscellaneous Expenditures: List specific amounts for each item. Examples of expenditures allowed include: publication costs, special fees (e.g., publication costs, pathology, computer time and scientific software, and equipment maintenance).

Contracts: If any portion of the proposed research is to be carried out at another institution, enter the total costs and provide a categorical breakdown on a continuation budget page.

Total Amount Requested: If the proposal is a multi-year proposal, budget totals should encompass the total of all years or requested funding.

Budget Justification: Briefly justify all items of equipment costing over \$500, and the need for personnel, supplies, travel, and other miscellaneous items.

ASSURANCES AND CERTIFICATION PAGE

Assurances on vertebrate animal use or human subject use are to be stated following the budget. All activities involving human subjects or vertebrate animals must be approved by an appropriate institutional committee before the application will be funded by CurePSP.

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Furthermore, compliance with current US Department of Health and Human Services guidelines for financial conflict of interest, recombinant DNA, research misconduct, and vertebrate animals is required. The assurances and certifications are made and verified by the signature of the institutional official signing the application.

Vertebrate animals: Every proposed research project involving vertebrate animals must be approved, by an appropriate Institutional Animal Care and Use Committee (IACUC), in accordance with Public Health Policy on Humane Care and Use of Laboratory Animals. IACUC approvals are valid for a maximum of three years. Provide the date of the most recent IACUC approval. All research supported by CurePSP (including subcontracted activities) involving vertebrate animals must be conducted at performance sites which are covered under an approved Animal Welfare Assurance.

Human subjects: All proposed research projects involving human subjects must be approved by the appropriate Institutional Review Board (IRB) before funding can begin. However, IRB approval may be pending at the time of submission. IRB approval must occur less than one year before submission and the IRB's requirement for continuing review must be satisfied for subsequent grant payments to be made.

BIOGRAPHICAL SKETCH PAGES

Submit an NIH-style biosketch for the PI and each collaborator, even if no salary support is requested. Each biosketch should not exceed two pages. Do not provide biosketches for consultants or individuals that provide only technical assistance.

Education and Training: Include all degrees awarded: list the year conferred, institution, and field of study, and for a Ph.D. degree, the name of the mentor. Also list postdoctoral fellowships, and residencies. List title of position, mentor's name, institution, and inclusive dates of training.

Positions and Honors: List in chronological order previous positions, concluding with present position. State duration, title, and institution and, if applicable, mentor or laboratory head. List any honors.

Publications: Cite only peer-reviewed publications. Begin each citation on a new line. If the number of publications will not fit in the available space, list only those that are most recent and/or relevant to the grant; indicate total number of publications (excluding abstracts, non-peer reviewed articles, or book chapters).

OTHER SUPPORT PAGE

CurePSP will not fund projects that have excessive scientific overlap with other previously or currently funded projects. Please list the following information for the PI and all collaborators:

Current Support: List all current awards; give the source of funds, grant number, title of project, period of time covered by the grant, the amount of direct cost support for current year and total grant period, and percent effort. In a brief paragraph, outline the goals of the project and for projects related to the current application, clarify that there is no funding overlap.

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Submitted and Pending Support: List all applications to other funding sources that have been submitted and those that have been approved but where funding is pending. Identify those applications to be considered on an either/or basis with the CurePSP application. For pending support that is either/or with the CurePSP application, only one award can be accepted if both are approved for funding.

RESEARCH PLAN PAGES

Limit Research Plan to 3 pages, single-spaced, not including references. There is no need to discuss PSP or CBD fundamentals. Proposals should be realistic in terms of work to be accomplished in the period of time for which support is requested. Although it is permissible to submit applications on an "either/or" basis with other agencies, proposals should be adjusted to fit CurePSP's term and budget constraints.

Specific Aims: List the objectives and goal of the research proposed and describe the specific aims briefly in order of priority.

Background and Significance: Concisely summarize and critically evaluate related work done by others and specifically state how the successful completion of the Specific Aims would advance scientific knowledge or clinical practice.

Preliminary Data: Preliminary data supporting specific hypotheses or demonstrating technical proficiency may be included. For investigator-initiated research proposals, preliminary data is encouraged but not required.

Research Design and Methods: Describe your proposed methods and procedures in sufficient detail to permit evaluation by other scientists. Discuss potential difficulties and imitations of the methods and procedures, and provide alternative approaches. Order your priorities, and estimate the length of time that you believe will be required to complete each specific aim. Although the time estimated should not exceed the term for which support is requested, it is helpful to state how this project fits in with your long term research goals.

REFERENCES PAGE

Each literature citation should include the authors' names, article title, book or journal, volume number, page numbers, and year of publication. Any standard format is acceptable. There is no page limitation for the list of references.

APPENDIX PAGES

Include letters of support from collaborators and consultants. Do not include reprints of full articles.

15. RESUBMISSION OF AN APPLICATION

Applications that are not funded may be resubmitted as new applications. These may or may not be revised from the original version. The Research Plan should mention that this is a

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resubmission and should briefly summarize whatever changes have been made. *The combined length of the Resubmission overview and the rest of the Research Plan is still limited to three pages.* In considering resubmitting an application, even with revisions, applicants are advised to consult the DRMA.

16. CHANGES TO THE APPLICATION

Withdrawal of application: Please advise CurePSP promptly, in writing, should you decide to withdraw your application for any reason. Your letter (or email) to the Director of Research & Clinical Affairs identified in the application acknowledgment letter should include your name, the application number, and the reason for withdrawal.

Change of address: Notify CurePSP in writing of any changes of address, email or phone number, following the submission of an application. Include your name and the application number.

Change of institution: If you have submitted a grant application and change your institution, provide CurePSP with a revised cover page.