The Children’s Tumor Foundation

SCHWANNOMATOSIS RESEARCH PROGRAM

APPLICATION FOR SCHWANNOMATOSIS GRANT

POLICIES AND GUIDELINES

The Children’s Tumor Foundation was established in 1978 as a national non-profit voluntary health organization whose primary goals are:

a) to promote and support research to find the cause and cure for NF1 and NF2.

b) to provide information and guidance to affected families and to educate the non-affected so that they may better understand the value of the disorder.

c) to act as a resource on NF for medical and healthcare professionals.

In order to achieve the goals in research, the Foundation provides limited, temporary financial support for innovative research relevant to the cause, pathogenesis or treatment of NF.

This application package includes the following policies and guidelines governing the Foundation's research program. Please detach this section from the award application and refer to it if you have questions about the award process. For questions not covered in these guidelines, please contact Stephanie Ellis at the Children’s Tumor Foundation, telephone 410-381-4476 or email sellis@ctf.org.

PROGRAM DESCRIPTION

Schwannomatosis is the third major form of the neurofibromatoses and causes schwannomas to grow on the nerve sheath. The genetic locus for schwannomatosis has yet to be identified. Once the locus for the disease has been defined, a wealth of studies will be made possible. The basic role(s) of the gene could be determined and possible modifier genes could be identified. Genetic testing for offspring of affected individuals would be possible, animal models could be developed, and translational research could lead to possible therapies for schwannomatosis.

The major presenting symptom of schwannomatosis is pain, which in many cases leads to first observation of schwannomas. Affected individuals usually have much greater problems with pain than with neurological deficit. Surgical management of schwannomatosis is often quite effective. When tumors are completely resected, pain often subsides, although it may recur if new tumors form. When surgery is not feasible, management in a multidisciplinary pain clinic is advisable. There is currently no accepted medical treatment or drug for schwannomatosis.
Research Grants will be awarded to new or established investigators who wish to pursue schwannomatosis research with an emphasis in one of the following areas:

- Genetic studies of schwannomatosis, including but not limited to:
  - The identification of the genetic locus or loci
  - Gene(s) identification and characterization
  - Gene interactions on chromosome 22, or with genes on other chromosomes

- Tumor studies of schwannomas, including but not limited to:
  - Studies that would expand current knowledge of schwannoma cell biology
  - Identification of factors that initiate or enhance tumor growth
  - Identification of agents that would inhibit initiation and growth of schwannomas
  - Identification or development of cell or animal models of schwannomatosis

- Pain research involving schwannomatosis, including but not limited to:
  - Identification of mechanisms involved in neuropathic pain in schwannomatosis
  - Pharmacological management of neuropathic pain
  - Nontraditional treatments for neuropathic pain

**SUBMISSION, REVIEW AND AWARD OF APPLICATIONS**

**SUBMISSION:** An original and fifteen (15) copies of the completed application must reach the Foundation no later than the date indicated below. The review schedule is as follows:

<table>
<thead>
<tr>
<th>Application Deadline:</th>
<th>April 15, 2005</th>
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<tbody>
<tr>
<td>Review by Research Advisory Board:</td>
<td>June, 2005</td>
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<tr>
<td>Review by Board of Directors:</td>
<td>June, 2005</td>
</tr>
<tr>
<td>Applicant Notified:</td>
<td>June, 2005</td>
</tr>
<tr>
<td>Earliest Activation Date:</td>
<td>July 2, 2005</td>
</tr>
</tbody>
</table>

Send completed applications to: Stephanie Ellis
Director, Schwannomatosis Research Program
Children’s Tumor Foundation
8829 Blue Sea Drive
Columbia, MD 21046

In addition, send one copy by email to: sellis@ctf.org

**REVIEW:** All applications are evaluated by the Research Advisory Board of the Children’s Tumor Foundation whose recommendations are reviewed by the Board of Directors for final approval and funding. Funding of awards is based on available funds, the priority score awarded each application, and the recommendations of the Research Advisory Board. Relevance of the proposed study to issues in Schwannomatosis is also considered in determining awards. All research awards are subject to observance of the regulations and policies of the Children’s Tumor Foundation related to that category of research support.

**PAYMENT OF RESEARCH GRANTS:** One award will be made for no more than $100,000. The payment will be made following written acceptance by the awardee and receipt by the Foundation of a signed copy of its patent policy agreement.

**REPORT DUE** August 2006

**REBUDGETING OF FUNDS:** The grantee is permitted flexibility in the utilization of funds in the research budget. Requests for changes from budgets submitted with the original
applications must be made in writing to the Foundation and must be approved in writing by the Foundation.

**EARLY TERMINATION OF AWARD:** In the event an award is terminated, the award amount will be prorated on the basis of the number of months it was in effect. Any deviations from the arrangement will require special prior approval from the Children’s Tumor Foundation.

**REFUND OF UNEXPECTED AWARD FUNDS:** All unexpended and uncommitted funds in the possession of the awardee at the end of the award period shall be returned to the Foundation. Exceptions to this rule may be authorized providing the request is received at least sixty (60) days prior to the end of the award period.

**CHANGE IN STATUS OF AWARD OR AWARDEE:** Any fundamental change in the purpose for which an award was originally made, or replacement of the Principal Investigator, must have prior written consent of the Foundation. Awards may not be transferred from one institution to another without prior written authorization from the Foundation.

**PERSONNEL COMPENSATED UNDER AN AWARD:** All personnel compensated in whole or in part under a grant shall be considered to be employees of the grantee's institution, and not of the Foundation, except for patents on discoveries supported by Foundation funds.

**PUBLICATIONS OR EXHIBITS OF AN AWARDEE:** When a paper or exhibit by an awardee, based on the work supported by a Foundation award, is accepted for publication or presentation before a scientific organization, 12 copies of said paper, or a suitable description of the exhibit, shall be forwarded to the Foundation on notice of such acceptance, together with the name of the publication or the organization accepting it, and the time and place of the meeting. This information shall be considered confidential by the Foundation until it is presented. All such papers and exhibits shall carry a credit line to the Children’s Tumor Foundation.

**PUBLICITY:** No awardee shall release for publication, other than through the usual professional or scientific journals, the results of his work without notifying the Foundation of his/her intention to do so and furnishing a copy of the material intended for release. All announcements to any media of public information pertaining to an awardee and/or work to be done or accomplished under a Children’s Tumor Foundation award must have the approval of the awardee, the awardee's institution, and the Foundation.

**FINANCIAL REPORTS:** A final financial report of award expenditures and a refund of any monies unexpended during the period of the award, must be submitted to the Children’s Tumor Foundation within 120 days after termination of the entire award. An annual financial report of total award expenditures and a refund of any monies unexpended during the period of the award must be submitted within 90 days after the award period. Financial reports should be signed by the responsible institutional financial officer, as well as the Principal Investigator. Interim accounting may be requested by the Children’s Tumor Foundation.

**OTHER SOURCES OF SUPPORT:** It is the responsibility of the Principal Investigator and the institution to inform the Children’s Tumor Foundation of possible conflicts relative to duplicate funding of this project by other funding agencies. Failure to advise the Foundation of other sources of support can result in loss of funds from the Children’s Tumor Foundation.
CHILDREN’S TUMOR FOUNDATION
SCHWANNOMATOSIS RESEARCH PROGRAM

APPLICATION FOR SCHWANNOMATOSIS GRANT

TITLE OF PROPOSED PROJECT:

INVESTIGATOR NAME:

TITLE:

ADDRESS:

TELEPHONE:

FAX NUMBER: E-MAIL:

DEGREES & FIELD(S) OF SPECIALIZATION:

SPONSORING INSTITUTION NAME:

ADDRESS:

ADDRESS WHERE RESEARCH IS TO BE PERFORMED (If Different):

TELEPHONE:

FAX: E-MAIL:

NAME & TITLE OF AUTHORIZED RESPONSIBLE ADMINISTRATIVE OFFICIAL:

NAME & TITLE OF AUTHORIZED RESPONSIBLE FINANCIAL OFFICIAL:

ADDRESS:

TELEPHONE:

PAYEE AS IT SHOULD APPEAR ON ALL CHECKS:

4
INSTITUTIONAL OFFICER TO WHOM ALL CHECKS SHOULD BE MAILED:

DOES THIS PROJECT INVOLVE HUMAN SUBJECTS?: YES_______ NO_______
(If yes, has project been cleared with sponsoring institution? YES ______ NO ______
Are legally acceptable consent forms and procedures enclosed with this application? ________

CERTIFICATION:
We, the undersigned, certify that (a) the statements contained herein are true and complete
to the best of our knowledge; (b) and we agree to accept the terms and conditions of the
Children’s Tumor Foundation in effect at the time of award of the Grant for which we hereby
apply.

Signature    Date

Investigator:______________________________________________________________

Department Chairman:_______________________________________________________

Official for Sponsoring Institution:_______________________________________________

USES OF FUNDS UPON ACCEPTANCE: It is agreed by the undersigned that all funds
received as a result of this application will be expended for research purposes as described
therein:

Signature    Date

Applicant: ______________________________________________________________

Financial Officer: _________________________________________________________

CHILDREN’S TUMOR FOUNDATION
SCHWANNOMATOSIS RESEARCH PROGRAM

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PLEASE INCLUDE THE FOLLOWING INFORMATION WITH THIS APPLICATION FORM:

1. Research Plan (Limited to 8 pages, exclusive of bibliography) should include:
   a. Abstract  (limit to 250 words)
   b. Description of project in lay terms (to be used by non-scientific Officers of the
      Foundation)
   c. Introduction
d. Specific Aims

e. Significance (Please emphasize implications for schwannomatosis)

f. Experimental Design & Methods

g. Facilities available to carry out proposed research

h. Decisions governing choice of experimental animals or human subjects (Attach approved consent form if human subjects are used in study).

i. Bibliography

j. Appendix (optional) – attach reprints of applicant’s relevant published material

2. Budget

a. Salaries

<table>
<thead>
<tr>
<th>Title of Position</th>
<th>% Effort</th>
<th>% of Salary</th>
<th>Fringe Benefits</th>
<th>Total</th>
</tr>
</thead>
</table>

Professional

Non-Professional

b. Equipment (list each item)

c. Supplies

d. Miscellaneous Expenses

e. Total Direct Costs (no indirect costs will be paid)

f. Total budgetary request

3. Justification of budget

a. Explain salary requests for all personnel for the year

b. Justify equipment requirements

4. Research Support

LIST ALL RESEARCH SUPPORT, CURRENT AND PENDING:

Please include:

a. All other sources of support

b. Title of project

c. Amount of support and percent effort of applicant

d. Period of support
e. Name of primary investigator

f. Indicate relationship of this proposed project to all current support and/or to any pending applications.

5. Curriculum Vitae for Each Investigator Listed on Grant Application