

**IRS Form 1023**  
**Application for Recognition of Exemption**  
**under Section 501(c)(3) of Internal Revenue Code**  
**Attachment A - Narrative Responses**

**Part I – Identification of Applicant**

8. The following individual was paid to provide advise on the organization structure and to draft the articles of incorporation and the bylaws:

- ▶ W. Thomas Wheeler, Attorney  
Wheeler & Engelhart, P.A.  
4940 Viking Drive, Suite 327  
Edina, Minnesota 55435  
Amount paid: \$1616.00 as of Feb 23, 2007

The following individual was paid to provide financial advice and to assist with tax form preparation:

- ▶ Dianne R. Hickok, CPA  
HLB Tautges Redpath, Ltd  
4810 White Bear Parkway  
White Bear Lake, Minnesota 55110  
Amount paid: \$1200.00

9a. The web site is under construction and not yet available: [www.newhoperesearch.org](http://www.newhoperesearch.org)

**Part II – Organization Structure**

1. The New Hope Research Foundation articles of incorporation are provided in Attachment B.
5. The New Hope Research Foundation bylaws are provided in Attachment C.

**Part III – Required Provisions in Your Organizing Documents**

1. The organizing document purpose is shown on page 1, Article II, Attachment B.
2. The organizing document dissolution clause is on page 4, Article IX, Attachment B.

**Part IV – Narrative Description of Your Activities**

The description of activities is provided in Attachment D. Background information and the basis for forming a non-profit research foundation to fund research is provided in Attachment E. A summary of the disease and the foundation may also be found in the brochure in Attachment F.

**Part V – Compensation and Other Financial Arrangements**

- 2a. There exists a family relationship between the board members. John G. Keimel, Chairman and President, is married to Ellen L. Kraft, Vice-Chair.
- 3a. The officers of the foundation include:
  - ▶ John G. Keimel, MS Biomedical Engineering, 8 hours / week, responsible for overall management, scientific overview, grant review board, and administration.
  - ▶ Ellen L. Kraft, MS Physiology, 4 hours / week, management, grant review board, and scientific overview.
- 5a. See attached copy (Attachment G) of the approved Conflict of Interest Policy.

## **Part VI – Your members and Other Individuals and Organizations that Receive Benefit**

- 1a. Grants or contracts that are aligned with the mission and charter of the New Hope Research Foundation (See Attachment D) may be approved for individuals. Examples of activities include:
  - o Directed research
  - o Clinical management and administration
  - o Regulatory affairs
  - o Administrative support directly related to research activities or clinical studies
  - o Laboratory analysis directly related to research activities or clinical studies
  - o Web-site creation and maintenance
  
- 1b. Grants or contracts that are aligned with the mission and charter of the New Hope Research Foundation (See Attachment D) may be approved for organizations. In no case will grants or contracts be awarded that may result in intellectual property being created that would restrict future patient access to the potential therapy. Examples of activities include:
  - o Directed research
  - o Clinical management and administration
  - o Regulatory affairs
  - o Administrative support directly related to research activities or clinical studies
  - o Laboratory analysis directly related to research activities or clinical studies
  - o Web-site creation and maintenance

## **Part VII – Your History**

The New Hope Research Foundation was newly formed on December 22, 2006.

## **Part VIII – Specific Activities**

- 4a. Fundraising will be conducted by direct requests to philanthropic individuals and organizations. These solicitations may be conducted through mail, e-mail, and personal contact. Government agencies, such as the National Institute of Health, may be requested to support research or clinical activities through their normal grant program. In addition, the New Hope Research Foundation web site will solicit individual donations.
  
- 4d. Fundraising will be based in Minnesota, Ramsey County. We will perform all fundraising activities exclusively for the New Hope Research Foundation.
  
10. The New Hope Research Foundation does not currently own any intellectual property. Contracts and Grants will not be awarded by the New Hope Research Foundation where exclusive ownership of intellectual property might block advancement of potential therapy or deny access to patients. To avoid this situation, consideration will be made during the award of grants and contracts for the New Hope Research Foundation to retain exclusive or non-exclusive rights to any intellectual property created during the conduct of the research or clinical activities. The intent this policy is to permit economical access for patients to future therapies. Licensing rights and royalties of any intellectual property owned by the New Hope Research Foundation will be based on its mission and charter and agreed upon by its management.

- 13b. Grants or contracts awarded to organizations for research or clinical investigation are to be directly aligned with the mission and charter of the New Hope Research Foundation.
- 13c. No contracts have yet been signed.
- 13d. To date, grants have been provided to:
- ▶ National Tay-Sachs and Allied Disease Association  
Regarding: Annual Meeting Medical and Research Update Session Sponsorship  
Relationship with New Hope Research Foundation or its employees: None
  - ▶ The Hospital for Sick Children  
Regarding: GM2 gene therapy related research grant  
Relationship with New Hope Research Foundation or its employees: None
- 13e. Grants and major contracts will be reviewed and approved by the Grant Review Board. The New Hope Research Foundation will maintain documentation of the approved grants and contracts.
- 13f. The current research grant proposal process is attached (Attachment H). The grants will require the recipients to use the grant funds only for the purposes for which the grant was made, to provide periodic written reports concerning the use of grant funds, to provide a final written report and an accounting of how grant funds were used, and to acknowledge the New Hope Research Foundation authority to withhold and/or recover grant funds in case such funds are, or appear to be, misused. Patient education grants to other recognized charitable organizations will be made without the need for complying with this research grant proposal process.
- 13g. The review and approval of grant proposals will be made through the New Hope Research Foundation Grant Review Board. This board will both review new requests and review ongoing activities to provide oversight that the project activities are aligned with the activities that were approved. Approved research grants will require periodic and final reports on the research.
- 14b. Research grants and contracts will be preferentially provided to United States organizations or individuals, but foreign research grants will be awarded in cases where unique capabilities for gene or related biochemistry research is not available in the United States. A single research grant has been awarded to:
- ▶ The Hospital for Sick Children  
Regarding: GM2 gene therapy related research grant  
Relationship with New Hope Research Foundation or its employees: None
- 14c. The research grant to The Hospital for Sick Children noted in 14b will have the research conducted at its associated research facility in Toronto, Canada.
- 14d. All prior contributors are aware and all future contributors will be made aware that a grant review process will determine how individual grants are awarded. Grants will be awarded through the Grant Review Board (See Attachment H) and will be aligned with the mission and charter of the New Hope Research Foundation.
- 14e. The selection process for grants includes an assessment of the individual or institution's capabilities to complete the proposed activity. The criteria will focus on the individual or institution's prior history and experience with the activity being proposed.
- 14f. Research grants will require a final report to be submitted to the New Hope Research Foundation. Individuals or institutions awarded grants for scientific research will also be encouraged to submit the results for peer reviewed publications and/or presentation.

## Part IX – Financial Data

### A. Statement of Revenues and Expenses (Projected for FY 2007, 2008, and 2009):

15. Two grants have already been provided in FY2007:
  - ▶ National Tay-Sachs and Allied Disease Association  
Regarding: Annual Meeting Medical and Research Update Session Sponsorship  
Amount paid: \$5,000
  - ▶ The Hospital for Sick Children  
Regarding: GM2 gene therapy related research grant  
Amount paid: \$4,021

An additional grant is anticipated prior to the end of the fiscal year 2007 (ending June 30, 2007):

- ▶ University of Minnesota  
Department of Pediatrics  
Regarding: GM2 gene therapy related research grant  
Amount to be paid: \$25,000

It is projected that major research grants will be made in FY 2008 and FY 2009 for research and clinical studies on gene therapy for GM2 gangliosidosis.

23. For FY 2007, the additional expenses not otherwise noted include the transportation, meals, and lodging for the scientific panel members and for facilitation of the research review meetings conducted in Boston (March 9, 2007) and Seattle (June 2, 2007).

### B. Balance Sheet (as of May 31, 2007)

5. Corporate stock assets noted in the financial data balance sheet includes:
  - ▶ 1116 Shares of Medtronic, Inc. common stock

## Part X – Public Charity Status

- 1b. The organizing document meets section 508(e) requirements by operation of Minnesota state law.
4. See part IV, Narrative Description of Activities, Attachment D, as a statement describing the proposed operations as a private operating foundation.

## Schedule H

### Section I

- 1a. Grants will be provided for specific research only. See the Grant Proposal Process, Attachment H.
  - 1b. Grants will be provided for specific research only. See the Grant Proposal Process, Attachment H.
  - 1c. Education loans will not be provided.
  - 1d. Proposal requests will be publicized through direct contact with scientists who are known to have experience and scientific publications in the area of interest, through open requests at scientific and medical conferences, and through patient support organizations that have physician participants.
  - 1e. See Attachment F for a brochure which was provided to scientists attending the recent National Tay-Sachs and Allied Disease Association meeting on April 20, 2007.
  - 1f. Grant proposals are submitted using the Grant Proposal Process, Attachment H.
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3. See the Grant Proposal Process, Attachment H.
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- 4a. See Grant Proposal Process, Attachment H, and Part IV, Narrative Description of Activities, Attachment D.
  - 4b. The number of research grants will be dependent on available assets and schedule of the master research plan.
  - 4c. The amount of each grant will be based on an estimate of the fair market cost of the research to be performed. These estimates will be based on itemized listing of direct costs and labor provided in the grant proposal.
  - 4d. Research grants will be provided once for a research activity; renewals will not be considered.
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5. See Part IV, Narrative Description of Activities, Attachment D, and the Grant Proposal Process, Attachment H.
  6. A grant review board currently includes the Chairman, John G. Keimel, and the Vice-Chair, Ellen L. Kraft. Additional members are currently being recruited. The board members will be composed of individuals knowledgeable in the science of gene therapy, lysosomal storage diseases, or the conduct of clinical or preclinical studies. The members will not be financially associated with the organizations requesting the grants or benefit financially by specific grant selections.