

The Hemispherectomy Foundation Medical Advisory Board By-laws

**The Medical Advisory Board is a Sub-Group of The
Hemispherectomy Foundation
PO Box 1239
Aledo, TX 76008**

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Table of Contents

I. PREFACE	3
II. CURRENT BOARD MEMBERS.....	4
III. PURPOSE, ROLES, AND DUTIES OF THE HEMISPHERECTOMY FOUNDATION MEDICAL ADVISORY BOARD	5
A. PURPOSE OF THE MEDICAL ADVISORY BOARD.....	5
B. ROLE OF THE MEDICAL ADVISORY BOARD.....	5
C. DUTIES OF THE MEDICAL ADVISORY BOARD	5
IV. BY-LAWS OF THE HEMISPHERECTOMY FOUNDATION MEDICAL ADVISORY BOARD	6
A. MEMBERSHIP	6
B. REMOVAL OF MEMBERS FROM THE BOARD	6
C. ATTENDANCE.....	6
D. ORGANIZATION OF THE BOARD	6
E. RULES OF ORDER.....	6
F. FOUNDATION NOTICE REQUIREMENTS.....	7
G. RESEARCH GRANTS	7
H. CONFLICTS OF INTEREST	7
I. CONFIDENTIALITY	7
IV. FINAL CHARGE TO MEMBERS.....	8

I. PREFACE

This document shall govern the conduct of The Hemispherectomy Foundation Medical Advisory Board, in conjunction with all applicable by-laws of Hemispherectomy Angels, Inc. (From here forward referred to as The Hemispherectomy Foundation). In the event that there is a conflict between the by-laws of The Hemispherectomy Foundation and the Medical Advisory Board, then the foundation by-laws shall take precedence. The active chairperson(s) of the medical advisory board shall be responsible for the enforcement of the provisions herein.

II. CURRENT BOARD MEMBERS

P. David Adelson, MD, FACS, FAAP
Frederick Andermann, OC., MD., FRCP(C)
Dr. Benjamin Carson
Harry T. Chugani, M.D.
Aaron A. Cohen-Gadol, M.D., M.Sc.
Moise Danielpour, M.D.
Stella, DeBode
Michel Duchowny, M.D.
Gerald Grant, M.D.
Adam L. Hartman, M.D.
Angel W. Hernandez, M.D.
George Jallo, M.D.
Eric H. W. Kossoff, M.D.
Deepak K. Lachhwani, MB.BS, MD
Jason T. Lerner, M.D.
Sean M. Lew, M.D.
Joseph R. Madsen, M.D.
Gary W. Mathern, M.D.
John S. Myseros, MD, FACS, FAAP
Jeffrey G. Ojemann, M.D.
Yong D. Park, M.D.
Phillip Lawrence Pearl, M.D.
Cynthia F. Salorio, Ph.D.
Russell P. Saneto, DO, PhD
Raman Sankar, MD, PhD, FAAN
Sandeep Sood, M.D.
Harry V. Vinters, M.D.
Howard L. Weiner, MD, FACS, FAAP
Angus A Wilfong, M.D.
Daniel Yoshor, M.D.
Sue Yudovin, R.N., M.N, C.P.N.P.

III. PURPOSE, ROLES, AND DUTIES OF THE HEMISPHERECTOMY FOUNDATION MEDICAL ADVISORY BOARD

A. PURPOSE OF THE MEDICAL ADVISORY BOARD

The purpose of the Hemispherectomy Foundation Medical Advisory Board is to support the Hemispherectomy Foundation and those families who are supported by the Hemispherectomy Foundation.

B. ROLE OF THE MEDICAL ADVISORY BOARD

The Hemispherectomy Foundation Medical Advisory Board serves as a representative link between the Hemispherectomy Foundation and the medical community. Its role is primarily advisory, however, they may, on behalf of the Hemispherectomy Foundation, actively engage in other activities that promote education, awareness, and other activities that benefit the foundation or the community of hemispherectomy families. The governing body of the Medical Advisory Board is the Board Members themselves, and it is their decisions that are implemented for the Medical Advisory Board. The Hemispherectomy Foundation Medical Advisory Board does not make decisions for the Hemispherectomy Foundation, however, their input is highly valued, especially on medical topics.

C. DUTIES OF THE MEDICAL ADVISORY BOARD

The duties of the Hemispherectomy Foundation Medical Advisory Board are as follows, but are in no way limited by this list. Many duties will be defined by the Medical Advisory Board as the need arises or as a member takes on duties in support of the Hemispherectomy Foundation or the families it supports.

1. Review Hemispherectomy Foundation website and other communications for medical accuracy.
2. Make recommendations regarding Medical Research Grants when Hemispherectomy Foundation Research Funding is available and the foundation is ready to award Grant money for medical research.
3. Promote Inter-Institution communication among the medical community world-wide in regards to Hemispherectomy topics.
4. Participate in appropriate activities that enhance the Hemispherectomy Foundation's and the Medical Community's ability to support families who are affected by Hemispherectomy surgery.
5. The Medical Advisory Board may recommend changes to these By-Laws, but may not change them without approval of the Hemispherectomy Foundation Board of Directors.

IV. BY-LAWS OF THE HEMISPHERECTOMY FOUNDATION MEDICAL ADVISORY BOARD

A. MEMBERSHIP

1. All members shall be duly appointed by the Hemispherectomy Foundation Board of Directors.
2. Because of the specific nature of this board, the term of appointment for the Medical Advisory Board members shall be unlimited.
3. To maintain membership on the Advisory Board, it is understood that members will accept reasonable responsibilities which may be delegated to them by the Chairperson(s) and agreed to by the member of the Medical Advisory Board.
4. The size of the Medical Advisory Board is not limited at this time.
5. Anyone on the Medical Advisory Board may nominate new member(s). The nomination should be sent to the Hemispherectomy Foundation Board of Directors.

B. REMOVAL OF MEMBERS FROM THE BOARD

1. The Hemispherectomy Foundation Board of Directors may change the membership of the board at any time.
2. Membership on the Board shall be considered vacated by a member upon the following:
 - Submission of a written resignation
 - Submission of emailed resignation
 - Recommendation by the Hemispherectomy Foundation Board of Directors

C. ATTENDANCE

The Medical Advisory Board is encouraged to communicate by email, chat rooms, and other virtual meeting and collaboration methods. However, no mandatory meeting will be scheduled for the Medical Advisory Board. If a meeting is deemed necessary, attendance shall not be mandatory, however, it is highly encouraged. Lack of participation in the Medical Advisory Board activities, over an extended period of time, may result in replacement of the seat.

D. ORGANIZATION OF THE BOARD

1. The Board shall elect a new chairperson or co-chairpersons every two years using the following procedure:
 - The current Chairperson(s) shall...
 - Email a Request for Nominations for the Chair(s) position(s).
 - Email Vote Request to all members of the Medical Advisory Board.
 - Transition leadership to the new Chairperson(s).
2. The Chairperson(s) shall preside over all Medical Advisory Board business.
3. The Chairperson(s) are the primary interface between the Hemispherectomy Foundation and the Medical Advisory Board.
4. The Chairperson(s) will appoint committees of which the chairperson shall be an ex-officio member.
5. The Chairperson(s) shall initiate and direct Medical Advisory Board activities.

E. RULES OF ORDER

Common courtesy and communication.
If a vote is required, 51% or greater carries the vote.

F. FOUNDATION NOTICE REQUIREMENTS

The Medical Advisory Board is required to give periodic updates to the Hemispherectomy Foundation Board of Directors as to current activities. The frequency and method shall be up to the Chairperson(s) and shall be dictated by circumstances and need.

G. RESEARCH GRANTS

Grants of all types, including medical research grants, are allocated, determined, and awarded and distributed solely by The Hemispherectomy Foundation Board of Directors. The Medical Advisory Board serves as a consulting entity ONLY when deciding merit, applicability, and value of proposed research.

H. CONFLICTS OF INTEREST

1. Being a member of the Medical Advisory Board does NOT exclude a member or member's institution from applying for a research grant.
2. If a conflict of interest exists with a member of the Medical Advisory Board and their duties, it is up to that member to inform the Hemispherectomy Foundation Board of Directors through the Medical Advisory Board Chair Person(s).
3. In a situation where a conflict of interest exists, the member in conflict should abstain from voting regarding the topic of interest.
4. All disputes should be resolved through the Medical Advisory Board. If a dispute cannot be resolved by the Medical Advisory Board members, then the Hemispherectomy Foundation Board of Directors will make the final judgment.

I. CONFIDENTIALITY

It is the duty of all members of the Medical Advisory Board to treat confidential information as such. Any information that a member is privileged to, as a result of being on the Medical Advisory Board, should be treated as confidential.

IV. FINAL CHARGE TO MEMBERS

As a member of the Hemispherectomy Foundation Medical Advisory Board, you should be ever mindful that this board is in place to serve the past, present, and future **families** that are faced with this radical brain surgery. Your service, as a member, comes in the form of your esteemed medical knowledge and experiences.

Although the membership is geographically, ideologically, and philosophically diverse, the Medical Advisory Board should always work toward the common good of our **families**, putting aside personal and institutional biases and differences.

Each family has had to face (or will face) an unthinkable decision; a decision that will change their lives forever. You have an obligation, in your membership, to conduct Medical Advisory Board business in **their** best interest, not those of yourself, your institution, or your career.

The Hemispherectomy Foundation would like to see this surgery replaced by an equally effective, but less debilitating seizure-control treatment. However, since that does not currently exist, we support efforts to improve the various procedures that generally fall under the term "hemispherectomy" or similar surgery.

The surgery, however, is but one aspect for the families that we support. The Hemispherectomy Foundation also encourages research into the diseases and conditions that may lead to hemispherectomy, such as Rasmussen's Encephalitis, Sturge-Weber Syndrome, HME, Cortical Dysplasia, Pediatric Stroke and other malformations, syndromes, and conditions.

Other important areas, where The Hemispherectomy Foundation encourages research includes, but is not limited to : Pharmaceutical Treatments, Neuropsychology, Physical Rehabilitation, Cognitive Rehabilitation, Family Life, Child Life, Neuro-Ophthalmology, and any other area that may benefit the children and families that we serve.

Because there will always be a finite amount of funding, it is up to this board and the Board of Directors of the foundation to best allocate the available funds. Constructive debate is encouraged, and as long as the families best interest is part of the debate, then good and rightful decisions will be forthcoming.