

Article I — Name and Purpose

Section 1. Name:

The name of the corporation shall be *Crazy by Chiari, Inc.* (hereinafter “the Corporation”).

Section 2. Purpose:

The Corporation is organized and operated exclusively for charitable, scientific, and educational purposes within the meaning of Section 501(c)(3) of the Internal Revenue Code of 1986, as amended (the “Code”). The specific purposes include, but are not limited to:

- Advocacy for awareness, education, and research concerning Chiari Malformation(s) and associated comorbidities.
- Providing support to patients, primary caregivers, and families impacted by Chiari Malformation and related conditions.
- Facilitating research partnerships and promoting advancement of scientific understanding.
- Maintain and enforce strict privacy, data protection, and informed consent protocols for any personal medical information, images, or narratives collected or shared in connection with its programs, research, or education efforts.
- Developing and distributing educational materials while protecting the Corporation’s intellectual property rights.

Article II — Board of Directors

Section 1. Powers and Duties:

The Board of Directors (the “Board”) shall have the power and duty to manage the affairs

and property of the Corporation, including oversight of policies, programs, and fiscal matters, consistent with these Bylaws and applicable laws.

Section 2. Number and Qualifications:

The Board shall consist of no fewer than three (3) and no more than five (5) directors. Directors shall be individuals committed to the mission and able to actively participate in governance.

Section 3. Terms of Office:

Directors shall serve for a term of three (3) years. Terms shall be staggered as feasible to ensure continuity. Directors may serve consecutive terms if re-elected by the Board.

Section 4. Election and Removal:

New directors shall be elected by a majority vote of the existing Board members. Any director may be removed with or without cause by a majority vote of the remaining Board members.

Section 5. Vacancies:

Vacancies occurring for any reason may be filled by majority vote of the remaining directors. A director appointed to fill a vacancy shall serve until the expiration of the predecessor's term.

Section 6. Resignation:

Any director may resign at any time by delivering written notice to the Board or President.

Article III — Officers

Section 1. Officers and Duties:

The officers shall be President, Vice President, Secretary, and Treasurer. Officers shall perform duties customarily associated with their positions and as further defined by the Board.

- **President:** Chief executive officer, responsible for overall leadership and presiding at meetings.
- **Vice President:** Acts in absence of President, supports leadership duties.
- **Secretary:** Maintains minutes, records, and official correspondence.
- **Treasurer:** Oversees financial affairs, ensures proper accounting and reporting.

Section 2. Election and Term:

Officers shall be elected annually by the Board from among the directors and serve a one-year term, with eligibility for re-election.

Section 3. Removal:

Officers may be removed by a majority vote of the Board at any time, with or without cause.

Section 4. Vacancies:

Vacancies in officer positions shall be filled by the Board.

Article IV — Committees

Section 1. Standing Committees:

The Board may establish committees to carry out the Corporation's work. Committees shall report regularly to the Board.

- **Fundraising Committee:** Plans and implements fundraising activities.
- **Advocacy Committee:** Develops and executes advocacy and awareness initiatives.
- **Medical Advisory Committee:** Provides expert guidance on medical and scientific issues.
- **Grants Committee:** Reviews and awards grants to individuals affected by Chiari Malformation or associated comorbidities—including patients and primary caregivers—for medical bills, travel expenses, or emergency relief. All applications that include medical documentation or personal health narratives must be accompanied by written or recorded consent for any data shared or referenced in consideration of a grant.
- **Scholarship Committee:** Administers scholarship programs for individuals affected by Chiari Malformation or related conditions pursuing academic goals in healthcare, research, or advocacy. Any application materials including medical history, personal diagnostic information, or test results must be submitted with proper written or recorded consent from the applicant before review.

Section 2. Appointment:

Committee members shall be appointed by the Board and may include directors and qualified external individuals.

Section 3. Authority:

Committees shall act within the scope of authority delegated by the Board and in compliance with all policies and laws.

Article V — Meetings

Section 1. Regular Meetings:

The Board shall meet at least once annually and may meet more frequently as determined by the Board.

Section 2. Special Meetings:

Special meetings may be called by the President or any two directors upon at least ten (10) days written notice.

Section 3. Notice:

Notice of meetings shall be provided by mail, email, or other electronic communication at least ten (10) days prior to the meeting.

Section 4. Quorum and Voting:

A majority of the directors shall constitute a quorum. Decisions require a majority vote of those present at a meeting where quorum is established.

Section 5. Meeting by Electronic Means:

Meetings may be held in person, by telephone, video conference, or other electronic communication if all participants can hear each other simultaneously.

Article VI — Conflict of Interest Policy

Section 1. Purpose:

To protect the Corporation's interest when it is contemplating a transaction or arrangement that might benefit the private interest of an officer, director, or key employee.

Section 2. Definitions:

A conflict of interest arises when a director, officer, or committee member has a personal, financial, or other interest that could impair independent judgment.

Section 3. Disclosure:

All directors, officers, and committee members must disclose any actual or potential conflicts of interest promptly to the Board.

Section 4. Procedure:

- The interested person shall disclose the conflict and relevant facts.
- The Board shall determine if a conflict exists.
- The interested person shall not participate in discussion or vote on the matter.
- The minutes shall reflect the disclosure, abstention, and any Board action.
- If a director or committee member is also a recipient, contributor, or source of personal health data for a Corporation project or publication, they must recuse themselves from votes or decisions directly involving that data, unless explicit consent (written or video-recorded) has been provided for such involvement and is properly documented.

Section 5. Annual Conflict of Interest Disclosure Form:

All directors, officers, and key employees shall annually sign a conflict of interest disclosure statement. A sample form follows:

Conflict of Interest Disclosure Statement

I, _____ hereby disclose that I:

- Have no conflicts of interest to report OR
- Have the following actual or potential conflicts of interest relating to my service with *Crazy by Chiari, Inc.* (describe):

I agree to disclose any conflicts that may arise in the future and abide by the Corporation's Conflict of Interest Policy.

Signed: _____ Date: _____

Article VII — Advocacy and Lobbying

The Corporation shall not participate in any political campaign on behalf of or in opposition to any candidate for public office. Advocacy activities shall be conducted in accordance with all federal and state laws applicable to 501(c)(3) organizations, ensuring such lobbying is insubstantial in relation to the Corporation's overall activities.

Article VIII — Patient Privacy and Data Protection

Section 1. Commitment to Privacy:

The Corporation shall maintain strict confidentiality and privacy of all patient and participant information collected through its programs, research, or outreach activities.

Section 2. Compliance:

The Corporation shall comply with all applicable federal, state, and international laws and regulations governing the collection, storage, sharing, and use of personal health information, including but not limited to the Health Insurance Portability and Accountability Act (HIPAA), where applicable.

Furthermore, **all medical information, data, images, test results, diagnostic reports, and personal health narratives shared during any of the Corporation's programs or projects shall be obtained only with the informed and recorded consent of the individual to whom the data pertains.** Acceptable forms of consent include:

- **Signed written consent forms**, either digital or physical; or
- **Recorded verbal consent via video**, which must clearly identify the individual, the scope of consent being granted, and the date of recording.

All consent forms and recordings shall be securely stored and linked to the corresponding data, and may be revoked by the individual at any time in accordance with revocation procedures outlined in the Corporation's data retention policy.

Section 3. Data Security:

The Corporation shall implement appropriate technical, administrative, and physical safeguards to prevent unauthorized access to sensitive information, including encryption, role-based access controls, and secure backup procedures.

Article IX — Research Partnerships and Intellectual Property

Section 1. Research Partnerships:

The Corporation may enter into written agreements with research institutions, medical professionals, and other entities to collaborate on advancing scientific understanding and patient support. All partnerships shall adhere to the Corporation's privacy, data handling, and informed consent standards. Any use of personal medical data or case studies in a research collaboration must be supported by recorded consent from the individuals whose information is involved.

Section 2. Ownership of Materials:

All educational materials, medical illustrations, logos, publications, and other creative works developed or commissioned by the Corporation shall remain the sole property of *Crazy by Chiari, Inc.*

Section 3. Use of Materials:

Research institutions and medical professionals may use the Corporation's materials for educational, research, or advocacy purposes provided that:

- Public credit is given to *Crazy by Chiari, Inc.* upon the first use.
- Subsequent uses of the materials by the same entity do not require repeated credit.

- Use of the materials does not imply endorsement by the Corporation unless expressly authorized.

Section 4. Permission:

Third parties seeking to use Corporation materials beyond the scope outlined above must obtain prior written permission.

Article X — Fiscal Policies

Section 1. Fiscal Year:

The fiscal year shall be January 1 through December 31.

Section 2. Financial Controls:

- All funds shall be deposited in accounts approved by the Board.
- Disbursements shall be made only upon proper documentation and authorized signatures.
- The Treasurer shall present financial reports at each Board meeting.
- Grants and scholarships involving personal medical disclosures must be approved only after verification of appropriate written or video-recorded consent, which shall be archived with financial documentation.

Section 3. Audit:

The Board may engage an independent auditor or accountant to review financial statements annually.

Article XI — Indemnification

To the fullest extent permitted by law, the Corporation shall indemnify any person who is or was a director, officer, employee, or agent of the Corporation against expenses (including attorneys' fees), judgments, fines, and amounts paid in settlement actually and reasonably incurred in connection with any proceeding by reason of the person's service in such capacity, provided the individual acted in good faith and in a manner reasonably believed to be in the best interests of the Corporation.

Article XII — Amendments

These Bylaws may be amended, altered, or repealed by a two-thirds (2/3) majority vote of the Board at any regular or special meeting, provided that written notice of the proposed amendment(s) is given to all directors at least ten (10) days prior to the meeting.

Article XIII — Dissolution

Upon dissolution of the Corporation, any remaining assets shall be distributed exclusively for exempt purposes within the meaning of Section 501(c)(3) of the Code, or to another organization organized and operated exclusively for charitable purposes, as determined by the Board.