

DOCUMENT RETENTION AND DESTRUCTION POLICY

Crazy by Chiari, Inc.

Aiding in the advocacy and advancement of research for Chiari Malformation(s) and Associated Comorbidities

[www.crazybychiari.com]

I. Purpose

The purpose of this Document Retention and Destruction Policy (“Policy”) is to ensure that records of **Crazy by Chiari, Inc.** are maintained, protected, and disposed of in accordance with:

- Federal and state legal requirements (including HIPAA, Sarbanes-Oxley, and IRS regulations),
- Best practices for nonprofit governance and health-related advocacy organizations,
- Ethical responsibilities to patients, advocates, volunteers, and donors,
- The core values of transparency, accountability, and data stewardship.

This Policy applies to all Board members, officers, volunteers, employees, and contractors.

II. Scope of Policy

This Policy applies to all physical and electronic documents, including but not limited to:

- Governance documents (e.g., bylaws, meeting minutes)
- Financial records
- Legal correspondence
- Medical advocacy data (e.g., anonymized patient experiences, consent forms)
- Personnel and volunteer records
- Communications (email, website messages, public statements)
- Media, photographs, and recordings

III. Retention Schedule

Category	Type of Document	Minimum Retention Period
Governance	Articles of Incorporation, Bylaws, IRS Determination Letter, Board Meeting Minutes, Resolutions	Permanent
Legal & Compliance	Contracts, Agreements, Insurance Policies, Conflict of Interest Disclosures	7 years after expiration or termination
Finance	Annual Reports, Tax Filings (Form 990), Audit Reports, Bank Statements, Invoices, Receipts	7 years
Medical Advocacy	De-identified Case Reports, Survey Data, Patient-Provided Stories (with consent)	5 years from final use or publication
Personnel /Volunteers	Applications, Background Checks, Waivers, Signed Policies	7 years after termination
Donor Records	Donation records, Acknowledgments, Pledge Agreements	7 years
Communications	Newsletters, Social Media Campaigns, Press Releases, Public Statements	3 years

Email	Correspondence related to decisions, finances, complaints, or legal matters	3 years (unless categorized elsewhere)
Media	Photos, Videos, Event Recordings (with consent)	5 years or until consent revoked

IV. Confidentiality and Security

All sensitive and confidential information—including but not limited to medical anecdotes, HIPAA-protected data, and private communications—must be securely stored, encrypted when digital, and protected against unauthorized access. Only authorized individuals shall access or manage such records.

V. Method of Destruction

When the retention period for a document expires, the document shall be destroyed using a method appropriate to its sensitivity:

- **Paper documents** containing personal or confidential data must be **shredded**.
- **Electronic records** must be **permanently deleted** from systems and any backups, using secure deletion methods.
- Consent forms or legal documents that are revoked or superseded must be **archived** with clear annotation and expiration tracking.

VI. Holds on Destruction (Legal or Investigative Holds)

In the event of litigation, audit, government investigation, or known legal risk, **Crazy by Chiari, Inc.** will immediately suspend destruction of relevant documents, even if the scheduled retention period has expired. All Board members and relevant staff will be notified of any such “Legal Hold.”

VII. Oversight and Compliance

The Board of Directors, through its Secretary or Governance Committee, shall oversee this Policy’s implementation and periodic review. Questions about interpretation or exceptions shall be directed to the Chair or legal counsel, as needed.

VIII. Violations

Failure to comply with this Policy—especially the unauthorized destruction of documents under legal hold—may result in disciplinary action or termination of service or contract. Intentional destruction of materials to avoid legal scrutiny is grounds for immediate dismissal and possible legal consequences.

IX. Review and Updates

This Policy shall be reviewed **at least every three (3) years**, or sooner if laws or best practices change. Revisions shall be approved by the Board of Directors and documented in meeting minutes.

Acknowledgment

By signing below, the undersigned acknowledges having read, understood, and agreed to abide by this Document Retention and Destruction Policy.

Name: _____

Signature: _____

Title/Role: _____

Date: _____

Organized by Crazy by Chiari, Inc.

[www.crazybychiari.com]



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