

# Cure Mucopolipidosis

Bylaws and Articles of Incorporation



**Cure**

MUCOLIPIDOSIS

2022

Email: [info@curemucopolipidosis.org](mailto:info@curemucopolipidosis.org)

Website: [www.curemucopolipidosis.org](http://www.curemucopolipidosis.org)

# Bylaws of Cure Mucopolysaccharidosis



## 1. NAME AND PURPOSE

The name and the purpose of the Corporation are set forth in the Articles of Incorporation.

## 2. PRINCIPAL OFFICE OF THE CORPORATION

The principal office of the Corporation shall be as designated by the Board of Directors.

## 3. MEMBERSHIP

**Membership Requirements:** Person eligible for Membership in the Corporation shall have an interest in Mucopolysaccharidosis.

**Classes:** There shall be one class of members and they shall be voting members.

**Voting:** Each Member shall have one vote. There shall be no proxy voting.

## 4. DIRECTORS

**Classes:** There shall be only one class of Directors.

**Number/Composition:** The Board shall be composed of no more than (9) persons and no less than three (3) persons. The specific number of Directors shall be determined from time to time by the Board.

**Election/Vacancies:** At each annual meeting, the Directors to serve for the ensuing year shall be elected by the existing directors, if a quorum is present.

**Term/Vacancies:** Each Director shall hold office for a term of (2) years or until a successor is duly elected. Vacancies occurring between annual meetings shall be filled by the Board and persons so elected shall fulfill the unexpired term of his/her predecessor.

## 5. VOTING:

Each Director shall have one Vote.

## 6. REMOVAL:

A Director may be removed with or without cause, as determined by a two-thirds (2/3) vote of the Board at any meeting at which there is a quorum.

## 7. RESIGNATION:

A Director may resign only by submitting a written letter of resignation to the President or Secretary or to the other Directors if the resigning Director is the President. The resignation shall take effect at the time specified in the written letter of resignation, and if no time is specified, at the time of the receipt of the letter by the Corporation or its President.

## 8. OFFICER:

**Election:** The Officers shall consist of a President, Vice President, Secretary, Treasurer, and other such additional Officers as created from time to time by a majority vote of the Directors. The Officers shall be elected annually by the Directors at the first meeting of the Directors following the annual meeting of the

Corporation. A person may hold more than one office in the Corporation but may not serve concurrently as both President and Vice President of the Corporation.

**Vacancies:** Any vacancy occurring in any office, for whatever reason, shall be filled by the Board of Directors and persons so elected shall fulfil the unexpired term of his/her predecessor.

**Term:** Officers shall serve a term of two (2) years.

**Removal:** Any Officer may be removed with or without cause, by a vote of two thirds (2/3) of the Board present at any meeting at which there is a quorum.

Resignation: An Officer may resign only by submitting a written letter of resignation to the President or Secretary or to the other Directors, if the resigning Officer is the President.

## 9. AUTHORITIES AND DUTIES

The officers shall have the authority and responsibility delegated by the Board and as stated in these Bylaws.

**The President shall:** Prepare the agenda for, preside at and conduct all meetings of the Board; sign all contracts and agreements in the name of the Corporation after they have been approved by the Board; normally serve as the representative of the Corporation in meetings and discussions with other organizations and agencies.

**The Vice President shall:** Perform the duties of the President if the President is unable to do so or is absent; perform such other tasks as may be assigned by the Board; and, at the request of the President, assist in the performance of the duties of the President.

**The Treasurer shall:** Be responsible for all funds of the Corporation and receive and deposit all such funds into the proper account; record and monitor receipts and disbursements from such account or accounts; keep accurate books and records of the finances of the Corporation; prepare a financial accounting for each Board meeting; and prepare all end of the year accounting and filing of all federal tax reports.

Other Officers shall: Perform such duties as may be specified by the Board or Officers given authority over to them.

## 10. MEETINGS

**Annual Meetings:** The Annual Meeting of the Corporation shall be held in the month of May of each year or at such time as soon as practical thereafter as determined by the Board of Directors.

**Regular Board Meetings:** Regular meetings of the Board may be held quarterly and may be scheduled more often by the President.

**Special Meetings:** Special meetings of the Board shall be held at any time and at any place when called by the President or by at least two-thirds (2/3) of the Directors. Business transacted at special meetings shall be confined to the purposes of the meeting stated in the notice of the meeting.

**Notice of Meetings:** Notices of regular Board meetings, including the annual meeting, shall be in writing and delivered at least fourteen (14) days and no more than (90) days before the day of the meeting. Notices of special meetings shall state that it is a special meeting being called and may be given orally or in writing at least 24 hours prior to the meeting time. All persons entitled to vote at the meeting must be mailed or otherwise delivered proper notice of the meeting.

**Waiver of Notice:** Whenever any notice is required to be given pursuant to the charter of the Corporation or these Bylaws or pursuant to applicable law, a waiver thereof in writing, signed by the person or persons entitled to such notice, whether before or after the time stated therein, shall be deemed equivalent to the giving of such notice. Neither the business to be transacted at nor the purpose of any meeting need to be set forth in the waiver of notice, unless specifically required by statute. The attendance of any person at any meeting shall constitute a waiver of notice of such meeting, except where such person attends a meeting for the express purpose of objecting to the transaction of any business on the ground that the meeting is not lawfully called or convened.

**Quorum:** At a meeting of the board, a quorum shall constitute one-third (1/3) plus (1) of the directors.

**Telephone/other communication Meetings:** Meeting by means of a conference telephone or similar communications equipment may take place if all persons participating in the meeting can hear each other at the same time. Participation in a meeting by these means shall constitute presence in person at a meeting.

## **11. CONTRACTS, LOANS, CHECKS AND DEPOSITS**

**Contracts:** The Board of Directors may authorize any officer or agent to enter into any contract or to execute and deliver any instrument in the name of and on behalf of the Corporation and such authority may be general or confined to specific instances. Any agreement, deed, mortgage, lease, or other document executed by one or more of the directors or by an authorized person shall be valid and binding upon the Board of Directors and upon the Corporation when Authorized or ratified by action of the Board of Directors.

**Checks and Drafts:** All checks, drafts, or orders are of money, notes or other evidence or indebtedness issued in the name of the Corporation, shall be signed by such officer or officers, agents of the Corporation and in such manner as shall from time to time be determined by resolution of the board. In the absence of such a determination by the Board, such instruments shall be signed by the President. A reconciliation shall be performed for each bank statement by one other than those authorized to sign the aforementioned instruments.

**Deposits:** All funds of the Corporation not otherwise employed shall be deposited from time to time to the credit of the corporation in such banks, trust companies, or other depositories as the Board of Directors may designate.

## **12. COMMITTEES**

The board of Directors may create such committees with such powers as it deems wise to have. The President shall appoint persons to chair and serve on those committees, including persons who are no Directors of the Corporation. All such appointments must be approved by the Board either prior to the appointment or ratified at the next Board meeting.

## **13. INDEMNIFICATION**

Any person (and the heirs, executors, and administrators of such person) made or threatened to be made a part to any action, suit, or proceeding by reason of the fact that he or she is or was a Director or Officer of the Corporation shall be indemnified by the Corporation against any and all liability and the reasonable expenses, including attorneys fees and disbursements, incurred by him or her (or by his or her heirs executors, and administrators) in connection with the defence or settlement of such action, suit or proceeding, or in connection with any appearance therein, except in relation to matters as to which it shall be adjudged in such action, suit, or proceeding that such Director or Officer is liable for negligence or misconduct in the performance of his or her duties. Such right of indemnification shall not be deemed exclusive of any other

rights to which the Director or Officer (or his or her heirs, executors, and administrators) may be entitled to apart from this Article.

**14. FISCAL YEAR**

The fiscal year of the Corporation shall be from January 1<sup>st</sup> to December 31<sup>st</sup>.

**15. ACTION WITHOUT MEETING**

Any action which may be properly taken by the Board of Directors assembled in a meeting may also be taken without a meeting, if consent in writing setting forth the action so taken is signed by all the Directors entitled to vote with respect to the action. Such consent shall have the same force and effect as a vote of the Directors assembled and shall be filed with the minutes.

**16. AMENDMENTS**

These Bylaws may be amended by a majority vote of the Board of Directors provided the proposed amendment(s) has (have) been submitted to the Directors in writing with written notice of the meeting to decide on the proposed amendment(s) at least fourteen (14) days and no more than ninety (90) days prior to the day of the meeting.

I the undersigned, being Secretary of the Corporation, hereby certify that the above is a true, complete and accurate copy of the Bylaws as adopted by the Board of Directors

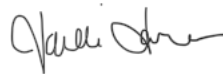
**On this day**                      **14<sup>th</sup> of July 2021**



**Signature:** \_\_\_\_\_

**Print Name:** Jenny Noble , Administrator of Cure Mucopolidosis

**On this day**                      **14th of July 2021**



**Signature** \_\_\_\_\_

**Print Name:** Jackie James, President of Cure Mucopolidosis

# ARTICLES OF INCORPORATION OF

## Cure Mucolipidosis.

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**First:** I the undersigned, Jackie James, whose post office address is 402 Park Ave, Belleville, IL 62220 being at least eighteen years of age, do hereby file these Articles with the intention of forming a non-profit, non-stock corporation under and by virtue of the general laws of the state of Illinois.

**Second:** The name of the corporation, hereinafter referred to as the Corporation is:

### Cure Mucolipidosis

**Third:** The post office address of the principal office of the Corporation is: 402 Park Ave, Belleville, IL. The resident agent, and individual actually residing in this state is Jackie James. The post office address of said resident agent is 402 Park Ave, Belleville, IL, 62220, United States.

**Fourth:** The Corporation is formed exclusively for charitable, educational, scientific, and non-profit purposes as defined under Section 501(c)(3) of the Internal Revenue Code of 1986, as amended or any corresponding provisions of any future United States Internal Revenue Law or Regulations thereunder, hereinafter collectively referred to as the Internal Revenue Code, as follows:

**A .** The Corporation plans to advance education and science and research concerning Mucolipidosis by engaging in programs that:

1. Promote and encourage research to find appropriate treatments and cures for Mucolipidosis.
2. Develop a confidential, secure patient history database of those affected by this disorder to support research efforts.
3. Disseminate to the medical profession current and newly developed methods concerning the detection, diagnosis, treatment and study of Mucolipidosis.
4. To work alongside and with the Mucolipidosis Collaborative Research Network (MCRN) for the benefit of Mucolipidosis.
5. Provide an information, supportive network for those suffering from Mucolipidosis, their families and the public.

**B.** The Corporation will undertake other projects, programs, and activates not inconsistent with Section 501 (c) 3 of the Internal Revenue Code and applicable state law, including the making of distributions to organizations that qualify as exempt organizations under Section 501 © 3 of the Internal Revenue Code, as the need to do so presents itself the opinion of the Board of Directors.

**C.** Except as provided in Sections 501(h) and 4911 of the Internal Revenue Code, no substantial part of the activities of the Corporation shall be the carrying on of propaganda or otherwise attempting to influence legislation. The Corporation shall not participate in or intervene in (including the publishing or distribution of statements) any political campaign on behalf of or in opposition of any candidate for public office.

**D.** Notwithstanding any other provision of these Articles, the Corporation shall not conduct or carry on any activities not permitted to be conducted or carried on.

1. by a corporation exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code, or
2. by a corporation contribution to which are deductible under Section 170(c)(2) of the Internal Revenue Code.

**Fifth:** In order to carry out the purposes, the Corporation shall have the following powers with the stated limitations:

- A. To solicit and accept, acquire by gift, donation, devise, grant, purchase, loan, or otherwise, any property without limitation.
- B. To make contributions, loans, or grants which are consistent with the purposes of the Corporation;
- C. To make agreements and contracts and incur liabilities.
- D. To do all things necessary or desirable to carry on and accomplish the purposes for which the Corporation is organized as the Directors of the Corporation may from time to time deem appropriate and which are not inconsistent with powers conferred upon a non-stock corporation by the General Laws of the State of Maryland and the requirements of the Internal Revenue Code;
- E. No part of the net earnings of the Corporation shall inure to the benefit of, or be distributable to any member, director, officer, trustee, or other private person, except that the Corporation shall be authorized and empowered to pay reasonable compensation for services actually rendered and to make payments and distributions in furtherance of the purposes set forth in Article Four.
- F. The Corporation is not organized for pecuniary profit. The Corporation shall not have capital stock or the authority to issue capital stock. The Corporation shall not have the power to declare dividends.

**Sixth:**

1. The affairs of the Corporation shall be managed under the direction of a Board of Directors which shall exercise all corporate powers except as conferred on, or reserved to the members or officers of the Corporation by law or the bylaws of the Corporation.
2. The initial number of Directors of the Corporation is three (3). The number of Directors may be increased or decreased pursuant to the Bylaws of the Corporation but shall never be less than three (3) or more than nine (9).
3. The Directors shall be elected, service for such terms, and have such qualifications as may be set forth in the Articles and the Bylaws of the Corporation.
4. The names of the initial Directors, who shall act until the first annual meeting or until their successors are chosen are as follows:
  - Jackie James
  - Jenny Noble
  - Nadia Jack

**Seventh:** The Corporation shall be composed of members. Qualifications for membership in the Corporation shall be defined in the Bylaws, no in no case shall membership be restricted on the basis of race, sex, sexual orientation, religion, or national origin.

**Eighth:** The duration and existence of the Corporation shall be perpetual.

**Ninth:** If the Corporation is dissolved or ended for any reason, the Board of Directors shall dispose of all of the net assets, after paying all liabilities, of the Corporation exclusively to such organization(s) which are organized and operated exclusively for charitable or educational purposes within the meaning of Section

501(c)(3) of the Internal Revenue Code, or the corresponding section of any future federal tax code, or shall be distributed to the federal government, or to a state or local government for a public purpose. Any such assets not so disposed of shall be disposed of by a Court of Competent Jurisdiction of the county in which the principal office of the corporation is then located, exclusively for charitable or educational purposes or to such organization(s), as said Court shall determine, which are organized and operated exclusively for such purposes.

**Tenth:** These Articles may be amended by a two-thirds vote of the Board of Directors provided the proposed amendment(s) has (have) been submitted to the Directors in writing with written notice of the meeting to decide on the proposed amendment(s) at least fourteen (14) days and no more than ninety (90) days prior to the day of the meeting

**Eleventh:** The Corporation shall adopt Bylaws for the further governance of the Corporation.

**IN WITNESS WHEREOF:** I have signed these Articles of Incorporation and acknowledged the same to be my own act on

Date: **14<sup>th</sup> day of July 2021**



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**SIGNATURE Administrator**

**Jenny Noble**

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**PRINT NAME**

Date: **14<sup>th</sup> day of July 2021**

---

**SIGNATURE Administrator**

**Jackie James**

---

**PRINT NAME**



## CURE MUCOLIPIDOSIS – BOARD CONTACT DETAILS

<b>President</b>	Jackie James 402 Park Avenue Belleville, IL 62220 United States
<b>Vice President Admin/Research</b>	Jenny Noble 167 Hollister Lane Ohauti, Tauranga, 3112 New Zealand
<b>Treasurer</b>	Kevin Gates 3921 Country Club Drive Lakewood, CA 90712-3827 United States
<b>Family Outreach</b>	Susan Kester 630 Old Waynesville Road, Jesup, GA 31546 United States
<b>Head of European Operations</b>	Truls Roll Sleipnersveg 82 5221 Nesttun Norway
<b>Communications</b>	Nadia Jack 24 Charles Cross Street Longburn Palmerston North 4412 New Zealand
<b>Research</b>	Daniel Peach New Zealand
<b>Fundraising</b>	Holly Thompson United States
<b>Fundraising</b>	Charlotte Gilbert United States
<b>Committee member for IT/Data</b>	Sue Weng United States



# OFFICE OF THE SECRETARY OF STATE

JESSE WHITE-Secretary of State

7328-946-7

OCTOBER 6, 2021

BRYTE BRIDGE  
7021 UNIVERSITY BOULEVARD  
WINTER PARK, FL 32792

RE CURE MUCOLIPIDOSIS

DEAR SIR OR MADAM:

ENCLOSED YOU WILL FIND THE ARTICLES OF AMENDMENT FOR THE ABOVE NAMED CORPORATION.

FEES IN THIS CONNECTION HAVE BEEN RECEIVED AND CREDITED.

SINCERELY,

JESSE WHITE  
SECRETARY OF STATE  
DEPARTMENT OF BUSINESS SERVICES  
CORPORATION DIVISION  
TELEPHONE (217) 782-6961

RECEIVED  
OCTOBER 11 2021  
SECRETARY OF STATE  
CORPORATION DIVISION  
1107 N. GULF BLVD.

**FILED**

OCT - 6 2021

JESSE WHITE  
SECRETARY OF STATE

Secretary of State  
Department of Business Services  
501 S. Second St., Rm. 350  
Springfield, IL 62756  
217-782-1832  
www.cyberdriveillinois.com

Remit payment in the form of a  
check or money order payable  
to Secretary of State.

File # 73289467 Filing Fee: \$25 Approved: JB

----- Submit in duplicate ----- Type or Print clearly in black ink ----- Do not write above this line -----

1. Corporate Name (See Note 1 on back.): Cure Mucopolipidosis

2. Manner of Adoption of Amendment:  
The following amendment to the Articles of Incorporation was adopted on 09/30/2021 in the manner  
indicated below (check one only): Month Day, Year

- By affirmative vote of a majority of the directors in office, at a meeting of the board of directors, in accordance with Section 110.15. (See Note 2 on back.)
- By written consent, signed by all the directors in office, in compliance with Sections 110.15 and 108.45. (See Note 3 on back.)
- By members at a meeting of members entitled to vote by the affirmative vote of the members having not less than the minimum number of votes necessary to adopt such amendment, as provided by this Act, the Articles of Incorporation or the bylaws, in accordance with Section 110.20. (See Note 4 on back.)
- By written consent signed by members entitled to vote having not less than the minimum number of votes necessary to adopt such amendment, as provided by this Act, the Articles of Incorporation, or the bylaws, in compliance with Sections 107.10 and 110.20. (See Note 5 on back.)

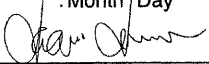
3. Text of Amendment:  
(a.) When an amendment affects a name change, insert the new corporate name below. Use 3(b.) below for all other amendments. \*Article 1: The Name of the Corporation is:

\_\_\_\_\_  
New Name

(b.) All amendments other than name change.  
If the amendment affects the corporate purpose, the amended purpose is required to be set forth in its entirety. If there is not sufficient space to add the full text of the amendment, attach additional sheets of this size.  
Article 4: Please see attached.

4. The undersigned Corporation has caused these Articles to be signed by a duly authorized officer who affirms, under penalties of perjury, that the facts stated herein are true and correct.

**All signatures must be in BLACK INK.**

Dated September 30th, 2021 Cure Mucopolidosis  
. Month Day Year Exact Name of Corporation  
  
 \_\_\_\_\_  
 Any Authorized Officer's Signature  
Jackie James, President  
 Name and Title (type or print)

5. If there are no duly authorized officers, the persons designated under Section 101.10(b)(2) must sign below and print name and title.

The undersigned affirms, under penalties of perjury, that the facts stated herein are true.

Dated \_\_\_\_\_, \_\_\_\_\_  
Month Day Year

Signature	Name and Title (print)
Signature	Name and Title (print)
Signature	Name and Title (print)
Signature	Name and Title (print)

**NOTES**

1. State the true and exact corporate name as it appears on the records of the Secretary of State BEFORE any amendment herein is reported.
2. Directors may adopt amendments without member approval only when the corporation has no members, or no members entitled to vote pursuant to §110.15.
3. Director approval may be:
  - a. by vote at a director's meeting (either annual or special), or
  - b. by consent, in writing, without a meeting.
4. All amendments not adopted under Sec. 110.15 require that:
  - a. the board of directors adopt a resolution setting forth the proposed amendment, and
  - b. the members approve the amendment.

Member approval may be:  
 a. by vote at a members meeting (either annual or special), or  
 b. by consent, in writing, without a meeting.

To be adopted, the amendment must receive the affirmative vote or consent of the holders of at least two-thirds of the outstanding members entitled to vote on the amendment (but if class voting applies, also at least a two-thirds vote within each class is required).

The Articles of Incorporation may supersede the two-thirds vote requirement by specifying any smaller or larger vote requirement not less than a majority of the outstanding votes of such members entitled to vote, and not less than a majority within each class when class voting applies. (Sec. 110.20)

5. When member approval is by written consent, all members must be given notice of the proposed amendment at least five days before the consent is signed. If the amendment is adopted, members who have not signed the consent must be promptly notified of the passage of the amendment. (Sec. 107.10 & 110.20)

Cure Mucopolidosis  
Articles of Amendment Attachment

ARTICLE 4 - Purpose(s) for which the Corporation is organized:

The corporation is organized exclusively for charitable, religious, educational and scientific purposes, including for such purposes, the making of distributions to organizations that qualify as an exempt organization under section 501(c)(3) of the Internal Revenue Code, or the corresponding section of any future federal tax code.

No part of the net earnings of the organization shall inure to the benefit of, or be distributed to its members, trustees, officers, or other private persons, except that the organization shall be authorized and empowered to pay reasonable compensation for services rendered and to make payments and distributions in furtherance of the purposes set forth in the purpose clause hereof. No substantial part of the activities of the corporation shall consist of the carrying on of propaganda or otherwise attempting to influence legislation, and the corporation shall not participate in, or intervene in, any political campaign on behalf of any candidate for public office. Notwithstanding any other provision of this document, the organization shall not carry on any other purposes not permitted to be carried on (a) by an organization exempt from federal income tax under section 501(c) (3) of the Internal Revenue Code, or corresponding section of any future federal tax code, or (b) by an organization, contributions to which are deductible under section 170(c) (2) of the Internal Revenue Code, or corresponding section of any future federal tax code.

The property of this corporation is irrevocably dedicated to charitable purposes and no part of the net income or assets of this corporation shall ever inure to the benefit of any director, officer or member thereof or to the benefit of any private person.

Upon dissolution of the corporation, assets shall be distributed for one or more exempt purposes within the meaning of section 501(c)(3) of the Internal Revenue Code, or the corresponding section of any future federal tax code, or shall be distributed to the federal government, or state or local government for public purpose. Any such asset not so disposed of shall be disposed of by the Court of Competent Jurisdiction of the county in which the principal office of the corporation is then located, exclusively for such purpose or to such organization or organizations as said Court shall determine, which are organized and operated exclusively for such purposes.