



Organizational Bylaws

ARTICLE I – NAME and PURPOSE

Section 1: The name of the organization shall be Haystack Project, Inc.

Address: 541 Powell Dr., Annapolis, MD 21401

Section 2: Haystack Project, Inc. is organized exclusively as a charitable and educational organization within the meaning of 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), for the following purposes:

- (a) To support a national network of rare and ultra-rare disease advocacy organizations;
- (b) To provide a mechanism for policy development and dissemination to external audiences so as to educate and inform healthcare payer policies and mechanisms so that they recognize the unique circumstances of extremely rare conditions and treatments, encourage innovation, and enable access to care for patients impacted by these conditions;
- (c) To enhance collaboration and information exchange among patient advocacy organizations within the rare and ultra-rare disease communities;
- (d) To amplify the voice of rare and ultra-rare disease patients on issues impacting availability of and access to treatment; and
- (e) To engage in any other activities that are not inconsistent with Section 501(c)(3) of the Internal Revenue Code and applicable state law.

ARTICLE II -- DIVERSITY. Haystack Project Inc. affirms its commitment to reflect society's diversity in its Board of Directors, staff, and programs. Consideration of diversity will reflect age, gender, culture, race or ethnic origin, geographic distribution and other factors relevant to the Foundation's mission.

ARTICLE III – MEMBERS

Membership shall only consist of the Board of Directors. Members will be elected to the board and each board member must be in good standing with Haystack Project Inc.

ARTICLE IV - ANNUAL MEETING

Section 1: Annual Meeting. The date of the regular annual meeting shall be set by the Board of Directors who shall also set the time and place.

Section 2: Special Meetings. Special meetings may be called by the Chair, President, or one third of the Board.

Section 3: Notice of each meeting shall be given to each board member, by email, not less than ten business days before the meeting

ARTICLE V - BOARD OF DIRECTORS



Section 1: Board Role, Size, Compensation. The Board is responsible for overall policy and direction of the Organization, and delegates' responsibility for day-to-day operations to the Officers. The Board shall have up to 6 and not fewer than 3 members. Board members must be over the age of 18.

CONFLICT OF INTEREST. Directors shall be subject to the organization's Conflict of Interest Policy, Code of Conduct policy, Confidentiality policy and Whistleblower policy, all of which are incorporated herein by reference. All Board members will receive a copy of these policies annually.

NO PRIVATE INUREMENT. The organization is not organized for profit and is to be operated exclusively for the charitable purposes stated in the Organization's Articles of Incorporation and in these bylaws. The net earnings of the Organization shall be devoted exclusively to charitable purposes and shall not inure to the benefit of any private individual. No Directors or person from whom the Organization may receive any property or funds shall receive or shall be entitled to receive any pecuniary profit from the operation thereof, and except as otherwise provided here with respect to the CEO who is ex-officio member of the Board of Directors, in no event shall any part of the funds or assets of the Organization be paid as salary or compensation to, or distributed to, or inure to the benefit of any member of the Board of Directors; provided however, that:

- a) reasonable compensation may be paid to any Director while acting as an agent, contractor, or Employee of the Organization for services rendered in affecting one or more of the purposes of the Foundation;
- b) any Director may, from time to time, be reimbursed for his or her actual and reasonable expenses incurred in connection with the administrative affairs of the Organization; and
- c) the Organization may, by resolution of the Board of Directors, make distribution to persons from whom the Organization has received contributions previously made to support its activities to the extent such distributions represent no more than a return of all or a pair or the contributor's contributions.

Section 2: Other Board Appointments: Haystack Project Inc. volunteers must volunteer successfully for one year, showing commitment, reliability and dependable service and have an excellent review before a board nomination can be accepted. Essential Members at Large and Advisory Members may be added and one year voluntary status waived if the board presents a justifiable reason for the addition and is accepted by a majority vote. Honorary Board Members may be nominated to the position if held in good standing once they have resigned or retired from the Board. The Board will set standards and criteria for which an honorary board member will follow by a majority vote. They must remain in good standing and positively represent the organization.

Section 3: Meetings. The Board shall meet at least three times a year. At least one of these meetings will be conducted in person.

Section 4: Board Elections. Election of new directors or election of current directors to a second term will occur as the first item of business at the annual meeting of the corporation. Directors will be elected by a majority vote of the current directors. All board members must complete and/or read and initial the conflict of interest policy, code of conduct, whistleblower, and confidentiality agreement.

Section 5: Terms. All Board members shall serve 2 year terms, with the exception of the Patient Representative Board member, but are eligible for re-election. Board members serving a two year terms, renewable up to 3 terms (total of 6 years). Patient representative will serve a term of one year, and participate in Board meetings as a non-voting member for a second year as 'immediate past



patient group representative' to the Board so that two patient representatives will be on the Board.

Section 6: Quorum. A quorum must be attended by at least 51% percent of the Board members before business can be transacted or motions made or passed.

Section 7: Voting. All issues to be voted on shall be decided by a simple majority of the board members.

Section 8: Notice. An official Board meeting requires that each Board member have written notice 10 business days in advance. The agenda to the meeting will be sent out five business days prior to the meeting. Both the agenda and the minutes will be made available to any sponsors or any other member of the public within 15 days of written request.

Section 9. Officers and Duties. There shall be four officers of the Board consisting of a Chairman, Treasurer, Secretary and Chief Executive Officer. One Board member may hold two of these roles. Duties are as follows:

The Chairman of the Board shall convene regularly scheduled Board meetings, special meetings and preside over or arrange for other members to preside at each meeting. The chairman will have oversight of the daily operations of the foundation and foster fundraising efforts. The chairman will be nominated by the Board of Directors and voted in as chair with a majority vote.

The Secretary shall be responsible for keeping records of Board actions, including overseeing the taking of minutes at all board meetings, sending out meeting announcements, distributing copies of minutes and the agenda to each Board members, and assuring that corporate records are maintained.

The Treasurer shall present a financial report at each Board meeting. Treasurer shall chair the finance committee, assist in the preparation of the budget, help develop fundraising plans, and make financial information available to Board members and the public. All documentation involving purchases and expenses must be given to the Treasurer within a reasonable amount of time (30 days) for budgeting purposes, otherwise membership will be terminated from the board if not received.

The President/CEO shall execute daily operations of the foundation. He/she may conduct -- or hire outside experts/consultants to conduct -- duties that include but are not limited to, recommending committees, representing the organization in public, with media, writing articles and attending functions on behalf of the organization as outlined in their contract. The President/CEO serves as an ex-officio voting member of the Board and should be excluded from discussions of compensation of an officer, Executive Committee member or any other employee. The President/CEO shall make such reports at the Board and Executive Committee meetings as shall be required by the Chairman or the Board. The President/CEO or a staff representative shall be an ad-hoc member of all committees. President/CEO will abide by the organizations accounting policy as follows: All transactions over \$5000 must have a Board of Directors majority vote, except in budgets approved by the board.

Section 11: Vacancies. When a vacancy on the Board exists, nominations for new members may be received from present Board members by the Chair and CEO two weeks in advance of a Board meeting with a qualifying resume. Nominees need to be individuals willing to meet the goals and fulfill the mission of the organization to the best of their ability. These nominations shall be sent out



to Board members with the regular Board meeting announcement, to be voted upon at the next Board meeting. These vacancies will be filled only to the end of the particular Board member's term.

Section 12: Resignation. Termination and Absences. Resignation from the Board must be in writing and received by the Chair and CEO. A Board member shall be dropped for excess absences from the Board. A Board member may be removed for other reasons, such as gross negligence of duties or misconduct. A majority vote of the remaining directors will decide upon removal from the board. A decision will be made either to remain until the end of their term and placed on a leave of absence, removed immediately or until the decision is reversed by the board because of conflict resolution.

Section 13: Special Meetings. Special meetings of the Board shall be called upon the request of the CEO or one-third of the Board. Notices of special meetings shall be sent out by the Chair or his/her designee to each Board member 2 days in advance or fewer if Board approves.

Section 14: Give-Get Policy. Beginning in 2020, each Board member will be expected to contribute to the foundation in a financially meaningful way.

Section 15: Confidentiality. The organization wishes to protect its confidential information. All board members and committee chairs must read, initial, and agree to adhere to the policy and sign a Confidentiality Agreement (NDA) to provide such protection to the organization upon the terms and conditions set forth in the agreement.

Section 16: In the event that Haystack Project Inc. ceases to exist any remaining assets shall be conveyed to a similar non-profit organization qualifying for tax exempt status under Section 501(c)(3) of the Internal Revenue Code, as amended, or as they may hereafter be amended.

ARTICLE VI - COMMITTEES

Section 1: The Board may create committees as needed. The CEO, or his/her designee, will be required to serve as a member of all active committees.

ARTICLE VII – AMENDMENTS

These Bylaws may be amended when necessary by a two-thirds majority of the Board of Directors. Proposed amendments must be submitted to the Secretary or his/her designee to be sent out with regular Board announcements.

ARTICLE VIII – COUNCILS/BOARDS

Section 1. The Board may create an Advisory Council, Corporate Council, Medical Advisory Board, etc. as needed. Any members of such will be non-voting members.

Section 2. The Board of Directors may by resolution designate one or more persons to the above noted Boards or Councils. They may be persons of talent, special skills or experience, position, rank, influence, connection or demonstrated interest. Such members will be non-voting members.



Section 3. Honorary Board: An Honorary Board of former members of the Board of Directors and others whose name would lend credibility may be appointed to an Honorary Board by The Board of Directors. The Board will set standards and criteria for which an honorary board member will follow by a majority vote. They must remain in good standing and positively represent the organization.

ARTICLE IX -- BOOKS OF RECORD, ANNUAL REPORT AND FISCAL YEAR

SECTION 1. The Board of Directors shall cause to be kept and preserved:

- a) Records of all proceedings of the Board of Directors, and its committees;
- b) All financial statements of the Organization; and
- c) Certificate of Incorporation and Bylaws of the Organization and all amendments and restatements; and
- d) Other records and books of account necessary and appropriate to the conduct of the corporate business.

SECTION 2. The Board of Directors will cause an annual report or the Federal 990 Tax Return to be conveyed to each Director within one hundred eighty (180) days of the close of each fiscal year. Such annual report shall contain: a statement of all assets and liabilities; principal changes in funds; income and expense statement; status of all funds held for restricted purposes; and any other such information as may be required by law, these Bylaws and/or for purposes of fulfilling the fiduciary responsibilities of the Directors.

SECTION 3. The fiscal year of the Organization shall be from January 1 to December 31 of each year

ARTICLE X -- CONTRACTS, CHECKS, DEPOSITS AND FUNDS, GIFTS AND PATENTS

SECTION 1. The Board of Directors authorizes the CEO of the Organization to enter into any contract or execute and deliver any instrument in the name of and on behalf of the Organization and such authority may be general or confined to specific instances. If the CEO is not able to fulfill his or her responsibilities, the Chair may execute these responsibilities.

SECTION 2. All checks, drafts or other orders for the payment of money, notes or other evidence of indebtedness issued in the name of the Organization, shall be signed by such officer or officers, agent or agents of the Organization and in such manner as shall from time to time be determined by resolution of the Board of Directors.

SECTION 3. All funds of the Organization shall be deposited to the credit of the Organization in such banks, trust companies, or other depositories as the Board of Directors may select.

SECTION 4. The Board of Directors may accept on behalf of the Organization any contribution, gift, bequest, or devise for the general purposes or for any special purpose of the Organization in accordance with the Organization's Gift Acceptance Policy.

When the Organization accepts a restricted donation, it shall use its best efforts to faithfully follow the restrictions of the donor as established for either principal or interest, or both, concerning the donation. The Organization shall not accept any restricted donation that is contrary to the current organization's policy or strategic direction. In the event a specified charitable purpose of a restricted donation becomes incapable of fulfillment, unnecessary, inconsistent with the charitable needs of the community and/or strategic objectives of the Organization or otherwise contrary to the Organization's policy, the Board of Directors may by



resolution modify any restriction or condition of distribution with respect to such gift, subject to approval by the Board of Directors. Advice of the Organization's executive staff shall be sought and other organization policies followed with regards to restricted gifts whose size and nature warrant such action.

SECTION 5. The Board of Directors shall have the authority to make grant disbursements on behalf of the Organization to such other charities and organizations as may be permitted under the Articles of Incorporation of the Organization in furtherance of the Organization's charitable purposes.

SECTION 6. All grant disbursements shall be made only upon a majority vote of the Board of Directors or by policy governing such grants adopted by the Board of Directors.

SECTION 7. The Board of Directors shall have full power and discretion to deal with any patents and copyrights coming within the ownership or control of this Organization, including direct exploitation of same or the licensing of others for such uses and upon such terms as the Board may determine.

ARTICLE XI -- INDEMNIFICATION OF OFFICERS, DIRECTORSS, COMMITTEE PERSONS, EMPLOYEES AND AGENTS

SECTION 1. The Organization shall indemnify and hold harmless each officer, Directors, committee person, employee or agent of the Organization against and from all loss, cost, and reasonable expenses hereafter incurred by him or her in the payment, settlement and defense of any claim, suit or proceeding brought against such person because such person is or has been such officer, Directors, committee person, employee or agent. The rights of indemnification and exoneration occurring under this Article shall apply whether or not such person continues to be an officer, Directors, committee person, employee or agent at the time any loss, cost or expense is suffered or incurred. Such rights shall not apply in relation to any matters as to which such officer, Directors, committee person, employee or agent shall be adjudged in final judgment in such suit or proceeding to not have acted in good faith or in a manner which he or she reasonably believed to be in and not opposed to the best interests of the Organization, and if the suit or proceeding is a criminal one, when such officer, Directors, committee person, agent or employee had reasonable cause to believe his or her conduct was unlawful. The limits of this protection align with the current Directors' and Officers' policy.

SECTION 2. The Organization shall indemnify any person who was or is a party or is threatened to be made a party to any threatened, pending, or completed action or suit by or in the right of the Organization to procure a judgment in its favor by reason of the fact that he or she is or was a Directors, committee member, officer, employee, or agent of the Organization, or is or was serving at the request of the Organization as a Directors, committee member, officer, employee or agent of another Organization, partnership, joint venture, trust or other enterprise against expenses, including attorney fees, actually and reasonably incurred by him or her in connection with the defense or settlement of such action or suit, if he or she acted in good faith and in a manner he or she reasonably believed to be in or not opposed to the best interests of the Organization, provided that no indemnification shall be made in respect of any claim, issue or matter as to which such person shall have been adjudged to be liable for negligence or misconduct in the performance of his or her duty to the Organization unless, and only to the extent that, the court in which such action or suit was brought shall determine upon application that, despite the adjudication of liability, that in view of all the circumstances of the case, such person is fairly and reasonably entitled to indemnification for such expenses which the court deems proper. The limits of this protection align with the current Directors' and Officers' policy.

SECTION 3. To the extent that a Director, committee member, officer, or employee or agent of the Organization has been successful on the merits or otherwise in defense of any action, suit or proceeding referred to in Section 1 or 2 above, or in defense of any claim, issue or matter therein, he or she shall be indemnified against expenses, including attorney fees, actually and reasonably incurred by him or her in



connection therewith. The limits of this protection align with the current Directors' and Officers' policy.

SECTION 4. Any indemnification under Section 1 or 2 above, unless ordered by a court, shall be made by the Organization only as authorized in the specific case upon a determination that indemnification of the Directors, committee member, officer, employee or agent is proper in the circumstances because he or she has met the applicable standard of conduct set forth in such sections. Such determination shall be made by the Board by a majority vote of a quorum consisting of Directors who are not parties to such action, suit or proceeding, or if such a quorum is not attainable or, even if attainable, a quorum of disinterested Directors so directs, by independent legal counsel and a written opinion.

SECTION 5. Any expense incurred by a Director,, committee member, officer, employee or agent in defending a civil or criminal action, suit or proceeding may be paid by the Organization in advance of a final disposition of such action, suit or proceeding as authorized by the Board in the specific case upon receipt of an undertaking by or on behalf of such individual to repay such amount unless it shall ultimately be determined that he or she is entitled to be indemnified by the Organization as authorized by the laws of the State of Maryland.

SECTION 6. The indemnification provided by this Article shall not be deemed exclusive of any other rights to which those seeking indemnification may be entitled under any bylaw, agreement, vote of disinterested Directors or otherwise, both as to action in the indemnitee's official capacity and as to action in another capacity while holding such office, and shall continue as to a person who has ceased to be a Directors, committee member, officer, employee or agent and shall inure to the benefit of the heirs, executors and administrators of such a person.

SECTION 7. The Organization shall purchase and maintain insurance on behalf of any person who is or was a Director, committee member, officer, employee or agent of the Organization, or is or was serving at the request of the Organization as a Directors, committee member, officer, employee or agent of another Organization, partnership, joint venture, trust or other enterprise against any liability asserted against him or her and incurred by him or her in any such capacity, or arising out of his or her status as such, whether or not the Organization would have the power to indemnify him or her against such liability under the provisions of this Article of Maryland's Nonprofit Organization Act.

ARTICLE XII -- WAIVER OF NOTICE

Whenever any notice is required to be given by these Bylaws or any of the corporate laws of the State of Maryland such notice may be waived in writing, signed by the person or persons entitled to said notice, whether before, at or after the time stated therein, or before, at, or after the meeting.

ARTICLE XIII -- AMENDMENTS TO BYLAWS

These Bylaws may be altered, amended or repealed and new Bylaws may be adopted by two-thirds of the Directors present at any meeting at which a quorum is present, provided that due notice of such meeting shall have been furnished to or waived by all Directors and that such notice or waiver thereof shall have included a statement that one of the purposes of such meeting was to consider such alteration, amendment or repeal.

ARTICLE XIV -- DISSOLUTION

Upon dissolution of the Organization, the Board of Directors shall, after paying or making provision for the payment of all of the liabilities of the Organization and giving whatever notice may be required by law, dispose of all of the assets of the Organization exclusively for the purposes of the Organization in such



manner, or to such organization or organizations formed and operated exclusively for charitable and educational purposes as shall at the time qualify as an exempt organization or organizations under Section 501(c)(3) of the Internal Revenue Code of 1986 (or the corresponding provision of any future United States Internal Revenue Code), as the Board of Directors shall determine. Any assets not so disposed of shall be disposed of by the Circuit Court of the County in the State of Maryland in which the principal office of the Organization is then located, exclusively for the purposes of the Organization in such manner, or to such organization or organizations, as said Court shall determine, which are organized and operated exclusively for such purposes.

ARTICLE XV – ADOPTION OF BYLAWS

These bylaws were approved and adopted at a meeting of the Board of Directors on:

Secretary: Bela Sastry Signature *Bela Sastry* Date June 8, 2021