BYLAWS OF THE SPINA BIFIDA ASSOCIATION OF AMERICA ("BYLAWS") Effective June 30, 2011 Revised December 5, 2015

ARTICLE I. NAME, SYMBOL, PURPOSES AND NATIONAL OFFICE

- SECTION 1. NAME. This Wisconsin Corporation shall be known as: SPINA BIFIDA ASSOCIATION OF AMERICA, INC. (hereinafter referred to as "SBA").
- SECTION 2. SYMBOL. Adopted March, 1976



SECTION 3. PURPOSES.

- A. Promote the acceptance, accessibility, inclusion and well-being of persons with Spina Bifida.
- B. Develop, maintain, and provide current information about Spina Bifida to promote public awareness.
- C. Encourage the development of improved treatment and trained teams to care for all affected by Spina Bifida.
- D. Promote the development of appropriate educational, vocational, and community support to encourage self-determination.
- E. Promote research for Spina Bifida and related secondary conditions.
- F. Promote the prevention of Spina Bifida through information and public education.
- SECTION 4. NATIONAL OFFICE. The SBA shall maintain a "National Office" which serves as the primary point of contact for the SBA.

ARTICLE II. MEMBERSHIP

- SECTION 1. MEMBERS. The SBA shall have the following members (each a "Member" and together collectively referred to as "Members"):
 - A. Each chapter of the SBA which meets the affiliation standards of the SBA and is in good standing at the time of each relevant SBA

Meeting (each an "Affiliated Chapter"); and

- B. Each SBA Director serving on the SBA Board of Directors (the "BOD") at the time of each relevant SBA Meeting.
- SECTION 2. REVOCATION OF MEMBERSHIP. The membership of any Member may be revoked in accordance with the following:
 - A. A Director or Officer may be removed as set forth in Article V, Section 6; and
 - B. An Affiliated Chapter's membership may be revoked by a twothirds majority vote of the BOD for cause including, but not limited to, failure to abide by the provisions of the Affiliation Agreement; provided that any revoked Affiliated Chapter has the right of appeal at the next regular BOD meeting. The appeal shall not be tabled. A two-thirds majority vote in favor of the appellant is required to reinstate an Affiliated Chapter's membership.
- SECTION 3. WITHDRAWAL OF MEMBERSHIP. An Affiliated Chapter may voluntarily terminate its association with SBA; provided that it follows the relevant "Termination of Agreement" provision in its Affiliation Agreement.

ARTICLE III. MEMBER VOTING POWERS

- SECTION 1. NATIONAL DELEGATION VOTING. The "National Delegation" shall consist of the following representatives from the Affiliated Chapters:
 - A. DELEGATES. Each Affiliated Chapter shall have two votes at SBA Meetings as follows: (i) each Affiliated Chapter shall have two delegates of its choosing as National Delegation representatives (each a "Delegate") and (ii) each such Delegate shall have one vote at SBA Meetings. No individual who is paid staff in any capacity with the SBA or an Affiliated Chapter shall serve as a Delegate.
 - B. PROXY DELEGATES. A Delegate from an Affiliated Chapter may appoint the other Delegate from the same Affiliated Chapter to serve as a proxy Delegate. Such proxy Delegate shall be empowered to cast all two votes of the Affiliated Chapter being represented at SBA Meetings. The relevant Affiliated Chapter shall notify the Secretary/Treasurer in writing of the proxy appointment in advance of all SBA Meetings.

SECTION 2. DIRECTOR VOTING. Each Director serving at the time of each relevant

SBA Meeting shall have one vote at such SBA Meeting. Directors are not entitled to appoint a Proxy Delegate.

- SECTION 3. RESPONSIBILITIES. The Members shall vote, in accordance with the voting rights set out in this Article III:
 - A. To elect the Slate of Elected Directors; and
 - B. On proposed Motions to amend the Bylaws and the Articles of Incorporation.

ARTICLE IV. SBA MEETINGS

SECTION 1. ANNUAL MEETING AND SPECIAL MEETINGS.

- A. SBA MEETINGS. The term "SBA Meetings" shall encompass both the "Annual Meeting and "Special Meetings" of the Members. The Annual Meeting or Special Meetings may be held in person, by means of conference telephone, or by any means of communication by which all persons participating in the meeting are able to hear one another, and such participation shall constitute presence in person at the meeting.
- B. ANNUAL MEETING. An Annual Meeting shall be held at a time and place determined by the Chair, with the BOD's concurrence, but in any event, an Annual Meeting shall be held no less than once per calendar year.

C. SPECIAL MEETINGS.

- 1. May be called by the Chair with the BOD's concurrence.
- 2. Shall be called upon the request of a majority of the BOD.
- 3. Shall be called upon a written request which has been signed by at least two-thirds of the Chairs or Presidents of the Affiliated Chapters.
- D. NOTICE OF MEETINGS. Notice of the time and place of SBA Meetings shall be given to all Members at least 30 days before the date of the meeting. Publication of the meeting date in the SBA news publication or by a letter or email to Members shall constitute notice.
- E. PARLIAMENTARIAN. The Immediate Past Chair shall serve as "Parliamentarian" at SBA Meetings. In the event that the

Immediate Past Chair is unavailable to serve as the Parliamentarian, the Chair shall appoint an alternative to fulfill this role. The Parliamentarian shall be the ultimate determiner of proper meeting procedures and decisional compliance with the Bylaws.

SECTION 2. VOTING.

- A. All votes shall be cast in person except as otherwise noted.
- B. The total number of votes present and entitled to be cast shall be the sum of the votes at that meeting.
- C. A quorum shall exist when the votes present and entitled to be cast at the meeting equal at least a simple majority of the total Delegates entitled to be at the SBA Meeting calculated from the records of Members in good standing.
- D. Once a quorum has been established, a quorum shall continue to exist even if the number of votes present at the meeting falls below a simple majority of the total Delegates entitled to be represented at the SBA Meeting calculated from the records of Members in good standing.
- E. All elections shall be decided by a simple majority of the votes entitled to be cast, unless specifically noted otherwise in the Bylaws.
- F. All votes shall be by voice vote or hand vote, unless noted otherwise in these Bylaws.
- G. VOTING BY MAIL. Members shall vote by mail on any subject requiring action by the Members when it is not feasible to call a SBA Meeting.
 - 1. The decision to vote by mail shall be at the sole discretion of the BOD.
 - 2. The Secretary/Treasurer shall supervise the distribution of written ballots and reference material on each issue, as well as voting instructions on each issue. First class mail addressed to each Member's official address shall constitute proper distribution.
 - 4. A deadline for the return of the ballots shall be set at 30 days from the initial postmarked mailing date of ballots.

- 5. All ballots received by the established deadline shall be counted. The Secretary/Treasurer shall have all ballots received by the established deadline opened and tabulated and shall promptly report the results to the Members and the BOD.
- 6. For the vote to meet "quorum" requirements and be valid, at least a simple majority of Members must participate in the vote.
- SECTION 3. SPECIFIC PROCEDURES AND VOTING RULES FOR SBA MEETINGS.
 - A. NOMINATING AND ELECTING DIRECTORS. See Article 5.
 - B. AMENDING THE ARTICLES OF INCORPORATION OR BYLAWS
 - 1. MOTIONS
 - a. SUBMISSION TO BOARD GOVERNANCE COMMITTEE. Motions to amend the Articles of Incorporation or Bylaws ("Motions") from Members must be received by the Board Governance Committee at least 90 days prior to a SBA Annual Meeting. The Board Governance Committee shall prescribe the manner for submitting Motions.
 - b. SUBMISSION TO THE BOD. The BOD must act on a Motion to amend the Articles of Incorporation or Bylaws prior to an SBA Annual Meeting. Any Motion approved by the Board Governance Committee must be submitted to the BOD by the Board Governance Committee no fewer than 60 days prior to an SBA Annual Meeting. A Motion requires at least a two-thirds affirmative vote of the BOD votes cast to be recommended to the Members for approval.
 - c. DISTRIBUTION. Proposed Motions shall be distributed to Members at least 30 days before an SBA Annual Meeting.
 - 2. VOTING. The Members must vote to amend the Bylaws or to change the Articles of Incorporation. A Motion to amend the Articles of Incorporation requires at least a two-thirds affirmative vote of the votes cast to be approved. A Motion to amend the Bylaws requires a majority affirmative vote of the votes cast to be approved.

ARTICLE V. BOARD OF DIRECTORS

- SECTION 1. SBA MANAGEMENT. Except as otherwise provided herein, all corporate powers shall be exercised by or under the authority of, and the affairs of the SBA managed under the direction of the BOD. The members of the BOD shall be "Directors".
- SECTION 2. DELEGATION OF DUTIES. The BOD may delegate certain duties to committees, councils, advisory boards, task forces, working groups, Officers and the President & CEO of the SBA in accordance with these Bylaws.

SECTION 3. DIRECTORS.

- A. QUALIFICATIONS. A Director must exhibit an interest in the SBA's concerns, purposes, goals and mission. Any of the following individuals may not be a Director:
 - 1. An individual who is a serving Director's spouse, parent (including mother and father-in-law), child (including son and daughter-in-law), sibling (including brother and sister-in-law) and first cousin whether related by blood, marriage or adoption, and anyone who shares a serving Director's home (each such person a "Family Member").
 - 2. An individual who is paid staff in any capacity with the SBA or an Affiliated Chapter.
 - 3. An individual who is a Family Member of paid staff in any capacity with the SBA or an Affiliated Chapter.
- B. NUMBER. The BOD shall consist of the number of Directors determined by the BOD from time to time; provided that (i) the addition or removal of Directors shall be in accordance with the other provisions of these Bylaws and (ii) notwithstanding any other provision of these Bylaws, the BOD shall comprise no less than 13 Directors and no more than 19 Directors at any time. The BOD shall aim, but not be obliged, to maintain between 16 and 19 Directors at all times.
- C. COMPOSITION. A Director may either be (i) appointed in accordance with this Article V, Section 3.C (each an "Appointed Director") or (ii) elected by the Members at an SBA Meeting in accordance with Article V, Section 3.E (each an "Elected Director"). The composition of Appointed Directors of the BOD

shall be determined as follows:

- 1. A member of the Professional Advisory Council to the SBA (the "PAC") chosen by the PAC shall serve as an Appointed Director. Upon BOD approval in accordance with Article V, Section 4, the PAC may appoint up to three members of the PAC to serve as Appointed Directors (including the Appointed Director referred to in Article V, Section 3.C.2).
- 2. Upon BOD approval in accordance with Article V, Section 4, a member of the PAC Research Committee chosen by the PAC Research Committee shall serve as an Appointed Director.

D. TERMS OF OFFICE; ELECTION; APPOINTMENT.

- 1. ELECTED DIRECTORS. Each Elected Director shall be elected to serve a 3 year term, except (i) in the case of vacancies filled under Article V, Section 5, and (ii) an Elected Director elected to the office of Chair-Elect may continue to serve as a Director until the completion of the Six-Year Cycle (as defined in Article VI, Section 1.C). The term for an Elected Director shall commence at the beginning of the calendar year immediately following that Elected Director's election.
- 2. APPOINTED DIRECTORS. Each Appointed Director shall be appointed to serve a minimum 1 year and maximum 3 year term, except (i) for vacancies filled under Article V, Section 5, and (ii) an Appointed Director elected to the office of Chair-Elect may continue to serve as a Director until the completion of the Six-Year Cycle (as defined in Article VI, Section 1.C). The term for an Appointed Director shall commence at the beginning of the calendar year immediately following that Appointed Director's appointment.
- 3. LIMITATIONS. No Director may serve more than 6 consecutive years except that the Chair-Elect, Chair, and Immediate Past Chair may serve as a Director until they have completed the Six-Year Cycle (as defined in Article VI, Section 1.C). Once a Director becomes Chair-Elect, he or she may complete the Six-Year Cycle without reelection. An individual may serve up to a maximum of 12 years as a Director and/or Officer and is thereafter ineligible to serve in such capacity except that the Chair-Elect, Chair, or Immediate Past Chair may serve as a Director until they have completed the Six-Year Cycle.

E. NOMINATING AND ELECTING DIRECTORS.

1. NOMINATIONS.

- a. SUBMISSION. The Board Governance Committee shall prescribe the manner for submitting nominations; provided that nominations may be submitted by Members, committees, councils, advisory councils, task forces, working groups, Officers, the President & CEO and the staff of the SBA.
- b. DEADLINE. The Board Governance Committee shall receive Elected Director nominations not later than 90 days before each Annual Meeting.
- c. SLATE OF DIRECTORS. The Board Governance Committee shall nominate a slate of directors for election by the Members as Elected Directors (the "Slate"). The persons put forward and number of proposed Elected Directors on the Slate shall be determined by the SBA Board Governance Committee, but always in accordance with the other provisions of these Bylaws.
- d. DISTRIBUTION. The Board Governance Committee shall ensure nominations are distributed to the Members at least 30 days before each Annual Meeting.

2. ELECTION.

- a. VOTE BY MEMBERS. Each person entitled to vote shall vote for or against the Slate as a whole, which vote shall occur at an Annual Meeting. If the Slate put forward at an Annual Meeting receives a simple majority of the votes cast by the Members at an Annual Meeting, each person on the Slate shall be elected as an Elected Director.
- b. FAILURE TO ELECT SLATE. Notwithstanding anything contained in these Bylaws, if the Slate is not elected, the Elected Directors, the Directors in office immediately prior to the relevant Annual Meeting, and who would have been replaced as Elected Directors by the Slate had the Slate been elected, shall remain in office, even though their terms as Elected Directors are scheduled to expire. An election for these Elected Director positions shall be held again at the following Annual Meeting in accordance with this Article V, Section 3.

SECTION 4. MEETINGS.

- A. SCHEDULE. The BOD shall meet a minimum of three times per year, two of which must be in person. One meeting shall be held in conjunction with the Annual Meeting. Other meetings will be held at a time and place set by the Chair, with the BOD's concurrence, in person, by telephone or by other electronic means.
- B. QUORUM. A majority of Directors shall constitute a quorum. A quorum may be broken if the number of Directors at the meeting falls below a majority and the only business that can then be transacted is adjournment.
- C. VOTING. Issues shall be decided by a simple majority affirmative vote of the Directors present, in person, unless specifically noted otherwise in these Bylaws.
- D. VIRTUAL OR ASYNCHRONOUS MEETINGS. Virtual or asynchronous meetings of the Board of Directors may be held for the purpose of addressing single topics with the participation of at least two-thirds of the Board of Directors and does not require advanced notice. Virtual or Asynchronous meetings may take place via telephone, internet or other technologically-assisted means of communication. Decisions rendered in virtual or asynchronous meetings shall be entered into the minutes of the next regular or special meeting of the Board of Directors. All Virtual or Asynchronous meetings open at the time of a regular or special meeting of the Board of Directors will be deemed closed without resolution.
- E. NOTICE OF MEETING. Notice of any meeting of the BOD shall be given in accordance with these Bylaws at least ten days in advance thereof by written or electronic notice to each director. Neither the business to be transacted at, nor the purpose of, any regular or special meeting of the BOD need be specified in the notice of such meeting.
- SECTION 5. VACANCIES. With the recommendation of the Chair and the majority approval of the BOD, a vacancy created by the departure of a Director or Officer may be filled by a replacement Director or Officer for the remainder of the departed Director's or Officer's term of office. In the event of a vacancy in the office of Chair-Elect, Chair, or Immediate Past Chair, the replacement Officer shall complete the remainder of the Six-Year Cycle (as defined in Article VI, Section 1.C).

SECTION 6. REMOVAL FROM OFFICE AND APPEAL PROCEDURES. A Director or Officer may be removed from office for cause by a two-thirds majority vote of the BOD. A Director who is removed from office shall also be removed from the membership. Any Director or Officer so removed has the right of appeal at the next regular BOD meeting. The appeal cannot be tabled. A two-thirds majority vote in favor of the appellant is required to reinstate a removed Director or Officer.

SECTION 7. RESPONSIBILITIES OF THE BOARD OF DIRECTORS.

- A. Determine an organizational mission and purpose.
- B. Develop strategic plans.
- C. Recommend and set policy.
- D. Review and revise SBA's organizational structure.
- E. Employ a President & CEO for such period of time and upon the terms and conditions as the BOD may determine.
- F. Provide leadership in and establish goals and programs for SBA fund raising efforts.
- G. Manage SBA income and assets to ensure adequate financial resources are available.
- H. Execute the duties assigned to the BOD in these Bylaws.
- I. Enhance the public image of the SBA and Spina Bifida in general.
- J. Exercise all corporate powers necessary to manage the affairs and property of the SBA.
- K. Establish and disband ad-hoc committees of the SBA, councils of the SBA, advisory boards, task forces and working groups.
- L. Carry out fiduciary duties and governance responsibilities not covered by the above, pursuant to applicable law.

ARTICLE VI. OFFICERS

SECTION 1. POSITION DESCRIPTION.

A. The "Officers" of the SBA shall consist of persons occupying the following positions:

- 1. "Chair";
- 2. "Chair-Elect";
- 3. "Secretary/Treasurer"; and
- 4. "Immediate Past Chair".
- B. The BOD may create other Officer positions.
- C. TERM OF OFFICE.
 - 1. Officers shall be elected by the BOD at the first BOD meeting following an Annual Meeting except in the case of vacancies filled under Article V, Section 5. The term of office for an elected Officer commences at the beginning of the calendar year immediately following the BOD meeting at which the Officer was elected.
 - 2. Persons elected as Chair-Elect shall serve in that position for a 2-year term, to be immediately followed by a further 2-year term as the Chair, to be immediately followed by a further 2-year term as the Immediate Past Chair (the "Six-Year Cycle"). A person may only serve one Six-Year Cycle.
 - 3. The Secretary/Treasurer and Officer positions created under Article VI, Section 1.B shall be elected to a 2-year term. Persons serving in the office of Secretary/Treasurer shall be limited to two 2-year terms.
- D. CONSTRAINTS ON DIRECTORS HOLDING OFFICE. Each Officer shall be a serving Director. A Director may hold only one office at a time.
- SECTION 2. RESPONSIBILITIES. The responsibilities of the Officers shall be determined by the BOD from time to time and include, but are not limited to, the following:
 - A. CHAIR.
 - 1. Generally supervise the affairs of the SBA including (i) preside over SBA, BOD, and Executive Committee Meetings, (ii) act as the primary communications link between the BOD and the CEO & President, (iii) coordinate communication between the SBA and outside entities, (iv) in consultation with the BOD, appoint members of committees, councils, and other task groups, (v) serve as an ex-officio member of all committees, (vi) encourage and supervise other Officers and Directors in establishing meaningful

programs that support SBA's strategic plans and (vii) work with the other Officers and Directors in completing their responsibilities as set forth in these Bylaws.

2. Prepare the agenda for SBA Meetings, BOD meetings and Executive Committee meetings.

B. CHAIR-ELECT.

1. In the absence or disability of the Chair, the Chair-Elect shall perform all the duties of the Chair; when so acting shall have all the powers of, and be subject to all the restrictions upon the Chair.

C. SECRETARY/TREASURER.

- 1. Serve as both SBA fiscal officer and compliance/record-keeping officer and provide leadership in these areas.
- 2. Keep and maintain, or cause to be kept and maintained, adequate books and records of the SBA including (i) the minutes of SBA and BOD meetings, (ii) Affiliated Chapter lists, addresses and related information (including such information as is necessary to determine which Affiliated Chapters meet current affiliation standards), (iii) committee, council, advisory board, task force, working group, Officer and President & CEO information including member information and meeting minutes where applicable, (iv) financial records and statements including adequate and correct accounts of the properties and business transaction of the SBA, including accounts of its assets, liabilities, receipts, disbursements, gains, losses, capital, retained earnings, and other matters customarily included in financial statements of organizations similar to the SBA.
- 3. Serve all notices of the SBA, supervise the tabulation of votes of the Members and report the results to the presiding Officer.
- 4. Serve as chair of the Business and Finance Committee.

D. IMMEDIATE PAST CHAIR.

- 1. Serve as chair of the Board Governance Committee.
- 2. Serve as the Parliamentarian at Annual Meetings.

ARTICLE VII. PRESIDENT & CEO

SECTION 1. GENERAL. The SBA, acting through the BOD, shall employ an individual to act as "President & CEO" of the SBA for such period of time and upon such terms and conditions as the BOD may determine. The President & CEO shall not be a Director.

ARTICLE VIII. COMMITTEES; COUNCILS; ETC

- SECTION 1. STANDING COMMITTEES. The following shall be standing committees of the SBA (i) Executive Committee (chaired by the Chair), (ii) the Business and Finance Committee (chaired by the Secretary/Treasurer), (iii) the Audit Committee (chaired by an individual external to the BOD), (iv) the Field Relations Committee (chaired by a member of the BOD), and (v) the Board Governance Committee (chaired by the Immediate Past Chair).
- SECTION 2. OTHER COMMITTEES. In addition to the abovementioned standing committees of the SBA, the BOD shall designate committees, advisory councils, task forces and working groups, as are deemed necessary or desirable from time to time.
- SECTION 3. SCOPE OF AUTHORITY. The BOD shall determine the scope of authority of each committee, council, advisory council, taskforce and working group contemplated by Article VIII, Section 1 and Article VIII, Section 2. The scope of authority of each such body shall be (i) recorded in writing, (ii) approved by the BOD and (iii) kept in the books and records of the SBA.
- **ARTICLE IX. BOOKS AND RECORDS** All SBA books and records may be inspected at the National Office for any proper purpose at any reasonable time.
- **ARTICLE X. FISCAL YEAR** The SBA fiscal year shall be the calendar year.
- **ARTICLE XI. CORPORATE SEAL** The SBA Corporate Seal shall bear the inscription "Spina Bifida Association of America."
- ARTICLE XII. INDEMNIFICATION To the extent covered by any existing "Officers and Directors" liability insurance policy purchased by SBA, the Directors, employees, and agents of SBA shall be indemnified by SBA for the deductible amount not covered by the coverage provisions of said insurance policy.
- **ARTICLE XIII. ADMINISTRATION OF FUNDS.** The receipt of any gift, devise, bequest, or other contribution of money or other property, or any legal or equitable estate therein by the SBA shall be held by the SBA. The

money and other property arising therefrom shall be handled and disposed of by the SBA in the promotion of the purposes provided in Article I, Section 3.