

UNITED STATES OF AMERICA

The State of Washington



Secretary of State

I, **STEVE R. HOBBS**, Secretary of State of the State of Washington and custodian of its seal, hereby issue this

ARTICLES OF INCORPORATION

to

THE ORDER OF THE SWNS FOUNDATION

A **WA NONPROFIT CORPORATION**, effective on the date indicated below.

Effective Date: 09/17/2026

UBI Number: 606 293 357



Given under my hand and the Seal of the State
of Washington at Olympia, the State Capital

Steve R. Hobbs, Secretary of State

Date Issued: 09/17/2026

ARTICLES OF INCORPORATION

The Order of the SWNs Foundation

*Filed with: Washington Secretary of State, Corporations and Charities
Division*

*Governing law: RCW Chapter 24.03A — Washington Nonprofit
Corporation Act*

Filed: September 17, 2026

ARTICLE 1 — NAME

The name of this corporation is:

The Order of the SWNs Foundation

This is the legal name of the organization as it will appear on all government filings, bank accounts, contracts, grant agreements, and official correspondence. The corporation may use a shortened name or doing-business-as (DBA) name in public communications, but the full legal name above governs all binding legal documents.

ARTICLE 2 — PURPOSE

What this corporation is organized to do

This corporation is organized exclusively for charitable, educational, and scientific purposes within the meaning of Section 501(c)(3) of the Internal Revenue Code of 1986 (or the corresponding provision of any future federal tax code).

The specific mission of this corporation is:

Reducing the diagnostic delay for patients with schwannomatosis and related neurofibromatous conditions through patient identification and awareness campaigns, medical education, clinical standards advocacy, research support, patient community development, and the evaluation of clinical provider compliance with published schwannomatosis diagnostic and treatment standards.

What “exclusively charitable, educational, and scientific” means

This corporation exists to serve the public — specifically patients with schwannomatosis and the medical community that serves them. It does not exist to generate profit for private individuals. Every dollar raised, every program run, and every decision made must serve this charitable mission. Activities that do not advance this mission are not permitted.

No private benefit — the non-inurement clause

No part of the net earnings of this corporation shall inure to the benefit of, or be distributable to, its directors, officers, or other private individuals, except that the corporation 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 herein.

In plain terms: no one who runs or governs this organization may use it to enrich themselves. Directors and officers may be paid reasonable compensation for actual work performed — but they may not receive distributions of profit, bonuses beyond reasonable pay, or any financial benefit that is not tied to legitimate services rendered to The Order of the SWNs Foundation.

No lobbying or political activity

No substantial part of the activities of this corporation shall be the carrying on of propaganda or otherwise attempting to influence legislation, and this corporation shall not participate in or intervene in any political campaign on behalf of or in opposition to any candidate for public office.

In plain terms: this corporation is explicitly permitted to lobby government for funding and policy — including advocating to Congress for DoD CDMRP schwannomatosis research appropriations, meeting with legislators about rare disease funding, and urging the public to contact their representatives. Lobbying for the corporation’s mission is a legitimate and expected activity.

The only restriction is proportion: lobbying may not become the primary activity. As long as the majority of time, money, and effort goes to patient education, clinical standards, community programs, and research support, lobbying for funding and policy is well within bounds.

This corporation may never endorse, oppose, or campaign for any political candidate. That prohibition is absolute. Advocating for funding and policy is permitted. Campaigning for candidates is not.

Note: Once 501(c)(3) status is granted, the corporation may file IRS Form 5768 (the 501(h) election) to replace the vague “no substantial part” standard with a specific dollar-amount safe harbor — typically 20% of exempt purpose expenditures.

Non-discrimination

This corporation shall not discriminate on the basis of race, color, national origin, sex, disability, age, religion, sexual orientation, gender identity, or schwannomatosis subtype in the administration of its programs, services, employment practices, or volunteer activities. This commitment applies to all programs and to all persons seeking access to services, assistance, or community participation.

Restriction to permitted activities

Notwithstanding any other provision of these Articles, this corporation shall not carry on any other activities not permitted to be carried on (a) by a corporation exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code of 1986, or (b) by a corporation contributions to which are deductible under Section 170(c)(2) of the Internal Revenue Code of 1986.

ARTICLE 3 — REGISTERED AGENT AND REGISTERED OFFICE

What a registered agent is and why it is required

Washington State law requires every nonprofit corporation to maintain a registered agent — a person or business located in Washington State who is authorized to receive legal documents, government notices, and service of process on behalf of the corporation. Failure to maintain a registered agent can result in administrative dissolution of the corporation.

This corporation's registered agent

The name of this corporation's registered agent is:

Northwest Registered Agent, LLC

The address of the registered agent and registered office in Washington State is:

**522 W Riverside Ave, Ste N
Spokane, WA 99201**

ARTICLE 4 — DIRECTORS

Board size

This corporation shall be governed by a Board of Directors consisting of not fewer than five (5) directors. The number of directors, terms, election procedures, and removal provisions shall be established in and governed by the Bylaws.

Initial directors

The names and addresses of the persons who shall serve as the initial directors of this corporation until successors are elected and qualified are:

Name	Address
Sherry Kinkade	[Address on file with WA Secretary of State]

Additional directors will be elected at the first organizational meeting of the Board, at which time the Board will be seated at its full founding composition.

ARTICLE 5 — DISSOLUTION

Distribution of assets upon dissolution

Upon the dissolution of this corporation, assets shall be distributed for one or more exempt purposes within the meaning of Section 501(c)(3) of the Internal Revenue Code of 1986, or shall be distributed to the federal government, or to a state or local government, for a public purpose.

In plain terms: if this corporation ever closes, every dollar and every asset it owns must go to another nonprofit with 501(c)(3) status, or to a government entity for public use. No assets may be distributed to directors, officers, or any private individual upon dissolution.

What happens if no distribution is arranged

Any such assets not so disposed of shall be disposed of by the superior court of the county in which the principal office of this corporation is then located, exclusively for such purposes or to such organization or organizations, as said court shall determine, which are organized and operated exclusively for such purposes.

ARTICLE 6 — LIABILITY OF DIRECTORS

The protection

A director of this corporation shall not be personally liable to the corporation for monetary damages for any act or omission in the director's capacity as a director, except in the following circumstances:

(a) Intentional misconduct. The act or omission constituted intentional misconduct by the director.

(b) Knowing violation of law. The act or omission constituted a knowing violation of law by the director.

(c) Improper distributions. The director authorized or approved a distribution of corporate assets that was made in violation of RCW Chapter 24.03A, where the distribution rendered the corporation unable to pay its obligations as they came due in the ordinary course of business.

(d) Improper personal benefit. The act or omission involved a transaction from which the director received a personal benefit in money, property, or services to which the director was not legally entitled.

Relationship to Washington State law

This Article reflects the protections available under RCW 24.03A.855 as enacted at the time of this filing (September 2026). If that statute is subsequently amended to expand director protections, this corporation shall be entitled to the benefit of those expanded protections.

ARTICLE 7 — INCORPORATOR

The name and address of the incorporator of this corporation is:

Sherry

Kinkade

[Address on file with WA Secretary of State]

Executed this 10th day of September, 2026.

Sherry Kinkade, Incorporator

BYLAWS

The Order of the SWNs Foundation

A Washington State Nonprofit Corporation

*Governing law: Washington Nonprofit Corporation Act, RCW Chapter
24.03A*

ARTICLE I — NAME AND OFFICES

SECTION 1.1 — NAME

The name of this corporation is **The Order of the SWNs Foundation** (the “Order” or “Organization”).

SECTION 1.2 — PRINCIPAL OFFICE

The principal office of The Order shall be located in Washington State at such address as the Board of Directors may from time to time designate. The Order may maintain additional offices as the Board deems appropriate.

SECTION 1.3 — REGISTERED AGENT

The Order shall maintain a registered agent in Washington State as required by RCW 24.03A.085. The registered agent and registered office may be changed by the Board of Directors at any time by filing the appropriate notice with the Washington Secretary of State.

ARTICLE II — PURPOSES AND LIMITATIONS

SECTION 2.1 — PURPOSES

The Order is organized exclusively for charitable, educational, and scientific purposes within the meaning of Section 501(c)(3) of the Internal Revenue Code, including the following purposes:

- (a)** To find schwannomatosis patients — particularly those who are undiagnosed, misdiagnosed, or isolated from appropriate care — through public awareness campaigns, clinician education, patient-facing tools, and medical curriculum advocacy;
- (b)** To raise and steward financial resources that support The Order's programs and provide direct assistance to schwannomatosis patients through the SWN Fund;
- (c)** To build and sustain the schwannomatosis patient community by connecting patients to each other, to research opportunities, and to advocacy resources, and by amplifying the collective voice of the community; and
- (d)** To advance the quality of clinical care for schwannomatosis patients by developing, publishing, and advocating for evidence-based standards of clinical expertise — and by evaluating whether providers and facilities that claim schwannomatosis expertise actually meet those standards.

These purposes are implemented through The Order's four missions: FIND the Lost SWNs, FUEL with Coin, FLOCK & Raise a Squawk, and FORGE the Standards.

SECTION 2.2 — LIMITATIONS

- (a)** The Order shall not carry on any activities not permitted to be carried on by a corporation exempt from Federal income tax under Section 501(c)(3) of the Internal Revenue Code.
- (b)** No part of the net earnings of The Order shall inure to the benefit of, or be distributable to, its directors, officers, or other private persons, except that The Order 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 herein.
- (c)** No substantial part of the activities of The Order shall be the carrying on of propaganda or otherwise attempting to influence legislation. The Order shall not participate in or intervene in any political campaign on behalf of or in opposition to any candidate for public office.

What this means in plain terms: The Order is explicitly authorized to lobby government for funding and policy — including advocating to Congress for DoD CDMRP schwannomatosis research appropriations, meeting with legislators about rare disease funding, urging the public to contact their representatives, submitting regulatory comments, and testifying before legislative bodies. Advocating for the schwannomatosis patient community through legislative and regulatory channels is a core activity of The Order. The only restriction is proportion: lobbying may not become the primary activity of The Order. As long as the majority of The Order’s time, money, and effort goes to patient education, clinical standards, community programs, and research support, lobbying for funding and policy is well within bounds.

The Order shall never endorse, oppose, or campaign for any political candidate. That prohibition is absolute. Advocating for funding and policy is permitted. Campaigning for candidates is not.

501(h) Election — Required Action After Determination Letter:

Once 501(c)(3) status is granted, the Board of Directors shall promptly file IRS Form 5768 (the 501(h) election). The 501(h) election replaces the vague “no substantial part” standard in this section with a specific, calculable expenditure safe harbor: The Order may spend up to 20% of its exempt purpose expenditures on lobbying, with no more than 25% of that amount on direct lobbying of legislators. Filing Form 5768 does not change what The Order is permitted to do — it provides legal certainty about exactly how much. The Secretary is responsible for ensuring Form 5768 is filed with or before The Order’s first Form 990.

SECTION 2.3 — DISSOLUTION

Upon the dissolution of The Order, assets shall be distributed for one or more exempt purposes within the meaning of Section 501(c)(3) of the Internal Revenue 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 the superior court of the county in which the principal office of the Organization is located, exclusively for such purposes or to such organization or organizations, as said court shall determine, which are organized and operated exclusively for such purposes.

SECTION 2.4 — CORE VALUES

The Order shall conduct all of its activities in accordance with the following core values. These are not aspirational statements — they are governance commitments that bind the Board, officers, staff, advisors, and volunteers in every decision, program, partnership, and publication.

(a) Evidence Over Assumption. Every clinical claim is sourced. Every standard The Order cites already exists in the published literature. The Order does not make up the rules — it measures the field against the rules the field already agreed to follow. When evidence is uncertain, The Order says so. When The Order is wrong, it corrects the record.

(b) Patient First. Patients' interests precede institutional comfort, organizational convenience, and clinician defensiveness. When any decision must be made — what programs to run, what standards to publish, what partnerships to accept, what findings to release — the question is: what serves patients? That question ranks above what is comfortable for existing institutions, above what is convenient for The Order's relationships, and above what is politically easy. This value governs decision-making when institutional interests conflict with patient interests — it does not displace scientific expertise. When clinical or scientific questions are at issue, "Evidence Over Assumption" governs The Order's methodology, and the Medical Advisory Board is The Order's check on the accuracy of its clinical claims. "Patient First" means The Order will publish solid, MAB-reviewed findings even when those findings are uncomfortable for clinical institutions — not that The Order claims scientific authority it does not have.

(c) All Patients. The Order's mission encompasses the full schwannomatosis spectrum as classified under the 2022 international consensus — including SMARCB1-SWN, LZTR1-SWN, SMARCE1-SWN, DGCR8-SWN, gene-negative (SWN-NEC), unclassified (SWN-NOS), and NF2-SWN.

SWN-NEC (Not Elsewhere Classified) designates patients whose genetic workup is complete but no causative mutation has been identified — reflecting that the full set of schwannomatosis-causing genes has not yet been discovered. These patients have schwannomatosis; their causative gene is simply unknown to current science. SWN-NOS (Not Otherwise Specified) designates patients whose genetic classification is incomplete or pending. Patients without a known gene mutation are fully within The Order's mission and are among those The Order serves with the greatest urgency.

No person shall be denied access to The Order's programs, assistance, or community resources on the basis of their schwannomatosis subtype or the presence or absence of an identifiable genetic mutation.

The Order directs its programs and resources with primary emphasis toward schwannomatosis subtypes where unmet need is greatest — those with the largest documented diagnostic delays, fewest designated clinical programs, and least developed research and advocacy infrastructure. This prioritization reflects The Order's commitment to reaching patients who remain most underserved. It does not constitute a restriction on the population The Order may serve, the educational content The Order may publish, or the community events The Order may promote.

(d) Accountability Without Malice. The FORGE the Standards mission holds the clinical community accountable to standards the science already demands. The Order is not in the business of punishing individuals. It is in the business of surfacing the structural conditions that allow failure to persist — and giving patients, advocates, and oversight bodies the tools to correct them.

(e) Radical Transparency. The Order's finances are public. Its methodology is public. Its findings are public. Its sources are cited. The Order operates without hidden agendas because the patients who trust it deserve to know exactly what it is doing and why.

(f) Flock Over Individual. A single schwannomatosis patient is a medical curiosity. The community together is a dataset, a constituency, and a voice. The Order builds the community because the community is more powerful than any of us alone.

(g) Dignity in Every Encounter. SWN patients have spent years in medical offices being disbelieved, dismissed, and misdiagnosed. The Order meets every patient where they are — in their pain, in their anger, in their uncertainty — without requiring them to be inspiring, optimistic, or grateful.

ARTICLE III — MEMBERSHIP

SECTION 3.1 — NO VOTING MEMBERS

The Order shall have no voting members. All rights and powers ordinarily vested in members under the Washington Nonprofit Corporation Act (RCW Chapter 24.03A) are vested in the Board of Directors.

What this means: Under RCW 24.03A, a nonprofit corporation may choose not to have a voting membership class. The Order makes that choice. No person holds “membership” in the corporate governance sense — there are no member votes, no member elections, and no membership rights under RCW 24.03A. All governance authority vests in the Board of Directors.

SECTION 3.2 — COMMUNITY PARTICIPANTS

The Order may establish categories of supporters, community members, patient community members, volunteers, and other non-voting participants in Order programs and activities. These categories are programmatic designations — they define someone’s relationship to Order programs, not their corporate governance status. They carry no voting rights, no governance authority, and no corporate membership rights under Washington law.

ARTICLE IV — BOARD OF DIRECTORS

SECTION 4.1 — POWERS

Subject to the limitations of the Articles of Incorporation, these Bylaws, and the Washington Nonprofit Corporation Act, the Board of Directors shall manage the affairs of The Order, exercise all corporate powers, and direct all Order activities.

SECTION 4.2 — NUMBER

The Board of Directors shall consist of no fewer than five (5) directors. The Board may by resolution increase the authorized number of directors above five. Directors shall be natural persons.

Transitional period: During the initial organizational period — from The Order’s date of incorporation through the earlier of (a) the date of The Order’s IRS determination letter or (b) one hundred eighty (180) days after incorporation — the Board may operate with as few as one (1) director (the Founder) while actively recruiting to the minimum of five (5). During this transitional period, all Bylaw provisions requiring a specific minimum number of directors shall be interpreted based on the actual number of directors then seated. The Order shall seat at least five (5) directors before applying for NORD affiliate or Platinum membership.

Note on NORD: The minimum of five (5) satisfies the requirement for NORD Platinum membership, which requires a minimum of five directors meeting at least twice annually.

SECTION 4.3 — QUALIFICATIONS

Directors shall be committed to the mission of The Order. No particular professional credential, educational background, or financial capacity is required. Directors should collectively bring a diversity of skills, perspectives, and experiences relevant to The Order’s four missions — including patient experience, medical expertise, scientific and clinical knowledge, legal knowledge, financial acumen, communications experience, and advocacy experience. The Order values board composition that bridges the patient community and the scientific community, recognizing that both are essential to the mission.

SECTION 4.4 — TERMS

Directors shall serve three-year terms. Terms shall be staggered so that approximately one-third of the Board rotates each year. Directors may serve a maximum of three (3) consecutive terms (nine years). After sitting out at least one full term, a former director is again eligible for election.

SECTION 4.5 — STAGGERED TERM SCHEDULE

At the first meeting of the Board at which directors are formally seated, the Board shall by lot or agreement divide directors into three classes:

- Class I: initial term of one year
- Class II: initial term of two years
- Class III: initial term of three years

Thereafter all terms are three years. The purpose of this initial division is to establish the stagger; Class I and Class II directors are eligible for full three-year terms upon re-election at the end of their initial short terms.

SECTION 4.6 — ELECTION

Directors shall be elected by the affirmative vote of a majority of directors then in office. Nominations may be made by any director or by the Board's Governance Committee. The Board will seek diverse nominees reflecting the qualifications and diversity of perspective described in Section 4.3.

SECTION 4.7 — REMOVAL

Any director may be removed from the Board, with or without cause, by a two-thirds (2/3) vote of all directors then in office. The director subject to removal shall receive written notice of the proposed removal and shall have the right to address the Board before the vote is taken.

SECTION 4.8 — RESIGNATION

Any director may resign by delivering written notice to the President or Secretary. Resignation is effective upon delivery unless the notice specifies a later date. Resignation from the Board does not terminate any other role the director may hold (such as an officer position, advisory body membership, or volunteer status) — those must be separately resigned if the director wishes to end them.

SECTION 4.9 — VACANCIES

Vacancies on the Board, including vacancies created by an increase in the number of directors, shall be filled by a majority vote of the remaining directors. A director elected to fill a vacancy shall serve the remainder of the vacant term and is then eligible for a full three-year term.

SECTION 4.10 — COMPENSATION

Directors shall serve without compensation for their service as directors. The Order may, however, reimburse directors for reasonable expenses incurred in connection with their service under The Order's Expense Reimbursement and Accessibility Policy. Nothing in this section prevents The Order from paying a director for other services rendered to The Order outside their director role, provided the compensation is approved by the Compensation Committee under The Order's Conflict of Interest Policy, Section 8.2.

ARTICLE V — MEETINGS OF THE BOARD

SECTION 5.1 — REGULAR MEETINGS

The Board of Directors shall hold at least four (4) regular meetings per year. The Board may establish a regular meeting schedule by resolution.

SECTION 5.2 — SPECIAL MEETINGS

Special meetings of the Board may be called by the President or by any two directors. Notice of special meetings shall be delivered to each director at least forty-eight (48) hours before the meeting by any reliable means of communication.

SECTION 5.3 — NOTICE OF REGULAR MEETINGS

Notice of regular meetings shall be delivered to each director at least seven (7) days before the meeting. Notice may be delivered by email, text, or other electronic communication accepted by the director.

SECTION 5.4 — QUORUM

A quorum for the transaction of business shall be a majority of directors then in office. The act of a majority of directors present at a meeting at which a quorum is present shall be the act of the Board, except as otherwise required by law or these Bylaws.

SECTION 5.5 — ACTION WITHOUT A MEETING

Any action required or permitted to be taken at a Board meeting may be taken without a meeting if all directors then in office consent in writing to such action. Consent may be given by email. Written consent shall be filed with the minutes of the Board.

SECTION 5.6 — REMOTE PARTICIPATION

Directors may participate in any Board meeting by telephone, video conference, or other electronic communication by which all participants can simultaneously hear each other. A director participating remotely is considered present at the meeting for quorum and voting purposes. Remote participation is the default option for any director who requests it, without requiring justification.

SECTION 5.7 — PATIENT HEALTH ACCOMMODATION

The Board recognizes that director health may vary due to schwannomatosis and related conditions. Directors experiencing health challenges are encouraged to participate remotely, submit written comments for inclusion in the record, or designate another director to represent their position on a specific matter. A director who is unable to participate in a meeting due to health shall not be penalized, provided the director otherwise meets attendance expectations of their Board Member Agreement.

SECTION 5.8 — MINUTES

The Secretary shall keep minutes of all Board meetings and distribute them to all directors within fourteen (14) days of each meeting.

ARTICLE VI — OFFICERS

SECTION 6.1 — OFFICERS

The officers of The Order shall be a President, a Secretary, and a Treasurer. The Board may create additional officer positions as needed. Officers need not be directors, except that the President shall be a member of the Board of Directors.

SECTION 6.2 — ELECTION AND TERMS

Officers shall be elected by the Board of Directors at the first Board meeting of each calendar year. Officers shall serve one-year terms and may be re-elected without limit.

SECTION 6.3 — REMOVAL

Any officer may be removed by a majority vote of the Board of Directors, with or without cause. The officer subject to removal shall receive written notice at least five (5) business days before the Board's vote, except in urgent circumstances where immediate removal is necessary to protect The Order.

SECTION 6.4 — PRESIDENT

The President shall be the principal executive officer of The Order and shall, subject to the direction of the Board, have general supervision and control of the business and affairs of The Order. The President shall preside at all meetings of the Board, may execute contracts and other instruments on behalf of The Order when authorized by the Board, and shall perform such other duties as are assigned by the Board.

SECTION 6.5 — SECRETARY

The Secretary shall keep the minutes of all Board meetings; give notice of meetings as required; maintain The Order's corporate records; file required reports and notices with state and federal agencies; and perform such other duties as are assigned by the Board.

SECTION 6.6 — TREASURER

The Treasurer shall have custody of The Order's funds; maintain accurate financial records; present a financial report at each regular Board meeting; prepare or oversee preparation of the annual budget and financial projections; ensure preparation and timely filing of all required tax returns and financial reports; and perform such other duties as are assigned by the Board.

SECTION 6.7 — EXECUTIVE DIRECTOR

The Board may hire an Executive Director who is not a member of the Board. The Executive Director shall be responsible for the day-to-day management of The Order under the supervision of the Board and shall have such authority and duties as the Board may designate. The Executive Director shall be accountable to and may be terminated by the Board.

SECTION 6.8 — FOUNDER

The designation of “Founder” is an honorary title that may be conferred by the Board upon the person or persons who established The Order. The Founder designation does not confer additional governance rights, voting rights, or veto power beyond those that attach to the Founder’s elected role (if any) as a director or officer.

SECTION 6.9 — RESIGNATION OF OFFICERS

Any officer may resign from their officer position by delivering written notice to the President or Secretary. If the resigning officer is the President, notice shall be delivered to the Secretary or, if the Secretary is unavailable, to any director. Resignation from an officer position is effective upon delivery unless the notice specifies a later date. Resignation from an officer position does not constitute resignation from the Board of Directors — a director who resigns as an officer remains a director unless they separately submit a director resignation under Section 4.8.

ARTICLE VII — COMMITTEES AND ADVISORY BODIES

SECTION 7.1 — STANDING COMMITTEES

The Board of Directors may establish standing committees to assist in carrying out The Order’s work. The Board shall define each committee’s scope and membership by resolution. Standing committees shall include at least one director.

SECTION 7.2 — COMPENSATION COMMITTEE

The Board shall maintain a Compensation Committee consisting of at least two disinterested directors. The Compensation Committee is responsible for reviewing and recommending to the Board all compensation paid to The Order’s officers, directors, and the Executive Director, in accordance with The Order’s Conflict of Interest Policy. No person may participate in the Compensation Committee’s deliberations regarding their own compensation.

Startup period: While the Board has fewer than five directors seated, the Compensation Committee shall consist of all disinterested directors then in office (excluding any director whose compensation is under review). For any given compensation matter, all directors except the affected individual collectively constitute the committee. The committee shall document its deliberations — including any comparability data reviewed — in the Board minutes, regardless of how many directors serve as the committee for that matter.

SECTION 7.3 — FINANCE COMMITTEE

The Board shall maintain a Finance Committee, chaired by the Treasurer, to oversee The Order's financial controls, budget, investments, and annual financial review. The Finance Committee shall consist of the Treasurer and at least one other director. During The Order's startup period, the Finance Committee may consist of the Treasurer and the President if no additional director is available to serve.

SECTION 7.4 — GOVERNANCE COMMITTEE

The Board may maintain a Governance Committee responsible for board development, director recruitment, and annual governance self-assessment.

SECTION 7.5 — ADVISORY BODIES

The following advisory bodies are established pursuant to these Bylaws. Advisory bodies are not committees of the Board and have no governance authority. They advise the Board and advance The Order's programs.

(a) Medical Advisory Board (The Consular Circle) — provides scientific, clinical, and medical expertise. Governed by the MAB Charter adopted by the Board.

(b) Patient Advisory Council (The Pathfinders) — provides patient community voice and lived experience. Governed by the Patient Advisory Council Charter adopted by the Board.

(c) Volunteer Council (The Bevy of SWNs) — coordinates The Order's volunteers. Governed by the Volunteer Council Charter adopted by the Board.

(d) Industry Partner Program — The Order may enter into formal Industry Partnership Agreements with pharmaceutical companies, medical device companies, and clinical research sponsors whose work is relevant to schwannomatosis patients, including facilitating patient access to clinical trial information and connecting patients to existing patient assistance programs. The Industry Partner Program is not an advisory body and does not confer governance rights, voting rights, or Board access. Industry partners operate under the specific terms defined in their Partnership Agreements and are at all times subject to The Order’s Industry Partnership Policy, Gift Acceptance Policy, and Conflict of Interest Policy, each as adopted by the Board.

Anti-Kickback Statute Compliance. All Industry Partnership arrangements shall comply with the federal Anti-Kickback Statute (42 U.S.C. § 1320a-7b(b)), which prohibits offering, paying, soliciting, or receiving remuneration — directly or indirectly — to induce or reward referrals of items or services covered by federal healthcare programs including Medicare and Medicaid. Specifically: (i) The Order shall not receive funding from an industry partner that is conditioned on, or tied to, patient enrollment in a specific clinical trial or the purchase of a specific product; (ii) the SWN Fund patient assistance program shall be administered independently of industry partner funding, with patient eligibility determined solely by patient need and not by the products a patient uses or trials a patient joins; (iii) financial support from industry partners shall not be earmarked for assistance to patients using a specific company’s product; and (iv) industry partner contributions shall be structured to qualify for applicable safe harbor protections under 42 CFR § 1001.952, including the charitable donation safe harbor where applicable. The Industry Partnership Policy adopted by the Board shall include written procedures for identifying and avoiding Anti-Kickback Statute violations and shall require annual compliance review. No Industry Partnership Agreement shall be executed without determination by the Board that the arrangement complies with these requirements.

(e) Academic and Research Partnership Program — The Order may enter into formal collaboration agreements, memoranda of understanding, data sharing agreements, and other partnership arrangements with academic medical centers, research universities, and government and nonprofit research institutions — including institutes and centers of the National Institutes of Health, university research programs, NF clinical network partners, and similar organizations. Academic and research partnerships may include joint research projects, patient registry participation, clinical trial coordination, co-investigator roles on grant applications, conference co-sponsorship, patient navigation collaboration, and any other activity consistent with The Order’s exempt purposes. Academic and research partners are subject to The Order’s Conflict of Interest Policy and applicable privacy and data-sharing laws. Academic and research partnerships do not confer governance rights or Board access.

The Board may establish additional advisory bodies as needed. Each advisory body shall be governed by a charter adopted by the Board.

SECTION 7.6 — DUAL SERVICE

A person may simultaneously serve as a member of the Board of Directors and as a member of one or more advisory bodies, provided the person is attentive to which role they are acting in at any given time. Dual service is not a conflict of interest.

ARTICLE VIII — CONFLICT OF INTEREST

The Board of Directors shall adopt and maintain a Conflict of Interest Policy that meets the requirements of IRS Form 1023. All directors, officers, and members of committees with board-delegated powers shall comply with the Conflict of Interest Policy. Each such person shall complete the annual disclosure statement required by the policy. The Conflict of Interest Policy is incorporated into these Bylaws by reference and shall be treated as an exhibit to these Bylaws.

ARTICLE IX — FINANCIAL MANAGEMENT

SECTION 9.1 — FISCAL YEAR

The fiscal year of The Order shall be the calendar year, January 1 through December 31.

SECTION 9.2 — FINANCIAL CONTROLS

The Board shall adopt and maintain a Financial Controls Policy establishing procedures for authorization of expenditures, signing authority, reimbursement of expenses, and financial oversight. No single person shall control both authorization and payment of any transaction.

SECTION 9.3 — SIGNING AUTHORITY

Contracts, checks, notes, and other instruments shall be signed by the President, Treasurer, or Executive Director as authorized by the Board. The Board may by resolution designate additional signing authority. Any expenditure exceeding \$5,000 shall require approval by the President or Treasurer. Any expenditure exceeding \$10,000 shall require approval by the Board.

SECTION 9.4 — ANNUAL FINANCIAL REVIEW

The Board shall ensure that The Order's financial statements are reviewed annually by an independent accounting professional. When The Order's annual gross receipts exceed \$500,000, the Board shall obtain a full independent audit.

SECTION 9.5 — THE FUEL FUND AND SUB-FUNDS

The Order shall maintain the **FUEL Fund** as its master organizational fund, receiving all donations and revenue and distributing to three designated sub-funds:

SWN Fund — patient access grants; covers travel, lodging, caregiver costs, and care gaps after insurance for schwannomatosis patients reaching an NF clinic, SWN specialist, or clinical trial site, or needing more assistance at home. This fund is designated for any work that will Find a Lost SWN, aid them in accessing treatment, connecting with the greater SWN community, and receiving any other assistance they need with their rare disorder.

Squawk Fund — community building, conference presence, advocacy event costs, legislative and Congressional engagement, and activities that amplify the SWN community's collective voice. This fund is designated for any work that will Raise a Squawk in the SWN community.

Standards Fund — clinical accountability work, physician education materials, EHR alert development, medical school and residency curriculum advocacy, and research co-investment across all schwannomatosis subtypes. This fund is designated for any work that will Forge the Standards in the SWN community.

Operational and administrative costs not attributable to a specific sub-fund are covered directly from the FUEL Fund. The Board may establish additional restricted or board-designated sub-funds within this structure by resolution. Each sub-fund shall be maintained in a separate account from general operating funds.

SECTION 9.6 — PROHIBITION ON PRIVATE INUREMENT

No part of the net earnings of The Order shall inure to the benefit of any private individual. Directors and officers may receive reasonable compensation for services rendered and reimbursement for expenses incurred in connection with The Order's business, but only as authorized under the Conflict of Interest Policy and the Expense Reimbursement and Accessibility Policy.

SECTION 9.7 — FISCAL SPONSORSHIP AUTHORIZATION

The Board of Directors is authorized to enter into fiscal sponsorship arrangements with organizations exempt under Section 501(c)(3) of the Internal Revenue Code, under which the sponsoring organization provides tax-exempt umbrella status for donations received in support of The Order's programs — during the period before The Order receives its own IRS determination letter or at any other time the Board determines fiscal sponsorship is in The Order's interest. All fiscal sponsorship arrangements shall be documented in a written agreement approved by the Board and shall comply with all applicable IRS requirements and The Order's Gift Acceptance Policy. The Order's relationship with NORD (National Organization for Rare Disorders), if established as a fiscal sponsorship, constitutes such an arrangement under this Section.

ARTICLE X — INDEMNIFICATION

SECTION 10.1 — RIGHT TO INDEMNIFICATION

The Order shall indemnify each director, officer, and employee of The Order who is made a party to any proceeding by reason of the fact that they are or were a director, officer, or employee of The Order, against expenses, judgments, fines, and amounts paid in settlement actually and reasonably incurred in connection with such proceeding, to the fullest extent permitted by Washington law.

Applicable statute: RCW 24.03A.630 incorporates by reference RCW 23B.08.500 through 23B.08.603 (Washington Business Corporation Act — indemnification provisions as applied to nonprofit corporations). Under RCW 23B.08.510 (permissive indemnification), a corporation may indemnify a director against liability incurred in a proceeding if: (a) the director acted in good faith; (b) in their official capacity, the director reasonably believed their conduct was in the corporation's best interests; and (c) in any criminal proceeding, the director had no reasonable cause to believe their conduct was unlawful. Under RCW 23B.08.520 (mandatory indemnification), a corporation shall indemnify a director who was wholly successful on the merits in the defense of any proceeding against reasonable expenses incurred. Under RCW 23B.08.570, these protections extend to officers, employees, and agents. The Order's indemnification obligation is coextensive with the protections available under RCW 24.03A.630 and the incorporated provisions of RCW 23B.08.500–23B.08.603, as those statutes may be amended from time to time to expand protections.

SECTION 10.2 — LIMITATION

Indemnification shall not be available if the person acted in bad faith, received improper personal benefit, knowingly violated the law, or voted for or assented to a distribution in violation of Washington law.

SECTION 10.3 — INSURANCE

The Order may purchase directors and officers liability insurance on behalf of its directors and officers. The purchase of such insurance is authorized even if The Order could not otherwise indemnify such persons.

ARTICLE XI — RECORDS

SECTION 11.1 — CORPORATE RECORDS

The Order shall keep at its principal office, or at such other location as designated by the Board:

- Articles of Incorporation and all amendments
- Bylaws and all amendments
- Minutes of all Board and committee meetings
- Annual financial statements and tax filings
- A list of all current directors and officers with addresses
- All adopted policies

SECTION 11.2 — RETENTION

Corporate records shall be retained in accordance with The Order's Document Retention and Destruction Policy.

SECTION 11.3 — INSPECTION

Any director may inspect and copy The Order's records for a purpose reasonably related to the director's duties. The Board may adopt a written policy governing inspection of records by other parties, consistent with Washington law.

ARTICLE XII — AMENDMENTS

SECTION 12.1 — AMENDMENT BY THE BOARD

These Bylaws may be amended by the affirmative vote of two-thirds (2/3) of all directors then in office at any meeting of the Board at which a quorum is present, provided that written notice of the proposed amendment has been delivered to all directors at least fourteen (14) days before the meeting.

SECTION 12.2 — CONSISTENCY WITH ARTICLES

No amendment to these Bylaws shall be valid if it is inconsistent with The Order's Articles of Incorporation or with applicable law.

SECTION 12.3 — ADVISORY BODY INPUT

Before amending any provision of these Bylaws that directly affects the rights, role, or structure of an advisory body, the Board shall notify the affected advisory body and provide a reasonable opportunity for comment.

ARTICLE XIII — ADOPTION AND CERTIFICATION

These Bylaws were adopted by the Board of Directors of
The Order of the SWNs Foundation on:

Date: _____

Signed by the initial director:

Sherry Kinkade,
Director President / Founder

[Address on file with WA Secretary of State]

Certified by:

Sherry Kinkade,
Secretary

FORM 1023 — PARTS II, III, V, VIII, AND X

The Order of the SWNs Foundation

EIN: 42-4978003 | State of Incorporation: Washington | Date of Incorporation: September 17, 2026

These sections accompany Part IV (Narrative Description of Activities), which is separately drafted. Together they constitute the substantive filing content.

PART II — ORGANIZATIONAL HISTORY

IRS Form 1023 Part II asks about the organization's formation and history.

The Order of the SWNs Foundation was incorporated in Washington State on September 17, 2026. EIN: 42-4978003.

Prior to formal incorporation, the Founder developed and launched the following educational resources as pre-incorporation program development:

- **orderoftheswns.com** — The Order's public website, including the SWN specialist directory, patient education content, clinical trial awareness information, and community hub
- **Flight of the SWN** — an online educational awareness game available free of charge at orderoftheswns.com
- **Discord community server** — a community space for schwannomatosis patients, families, and caregivers

These activities were educational in nature and consistent with the charitable purposes for which The Order was subsequently incorporated. No donations were solicited or accepted prior to incorporation. No tax-deductible donations have been accepted pending receipt of the IRS determination letter. All pre-incorporation assets and activities were carried forward into the incorporated entity.

PART III — REQUIRED PROVISIONS IN YOUR ORGANIZING DOCUMENT

IRS Form 1023, Part III asks you to confirm that your organizing document contains the required provisions and to cite their location. All required provisions are in the Bylaws of The Order of the SWNs Foundation (adopted [date]).

Line 1 — Purpose Statement

Does your organizing document contain a statement of your purpose?

Yes.

Location: Bylaws, Article II, Section 2.1

Text of purpose clause:

The Order is organized exclusively for charitable, educational, and scientific purposes within the meaning of Section 501(c)(3) of the Internal Revenue Code, including the following purposes:

(a) To find schwannomatosis patients — particularly those who are undiagnosed, misdiagnosed, or isolated from appropriate care — through public awareness campaigns, clinician education, patient-facing tools, and medical curriculum advocacy;

(b) To raise and steward financial resources that support The Order's programs and provide direct assistance to schwannomatosis patients through the SWN Fund;

(c) To build and sustain the schwannomatosis patient community by connecting patients to each other, to research opportunities, and to advocacy resources, and by amplifying the collective voice of the community; and

(d) To advance the quality of clinical care for schwannomatosis patients by developing, publishing, and advocating for evidence-based standards of clinical expertise — and by evaluating whether providers and facilities that claim schwannomatosis expertise actually meet those standards.

Supplemental purpose statement for IRS Part I:

The Order of the SWNs Foundation is organized to serve patients with schwannomatosis — a rare genetic disorder affecting approximately 1 in 70,000 people — by reducing the documented 16.7-year median diagnostic delay, connecting isolated patients to specialist care and community, and holding the clinical community accountable to evidence-based standards of care. Schwannomatosis is distinct from and frequently confused with other forms of neurofibromatosis. The Order serves all schwannomatosis subtypes, with primary focus on those with the least-developed clinical and advocacy infrastructure: SWN-SMARCB1, SWN-LZTR1, SWN-SMARCE1, SWN-DGCR8, gene-negative (SWN-NEC), and unclassified (SWN-NOS).

Line 2 — Prohibition on Private Inurement

Does your organizing document prohibit private inurement?

Yes.

Location: Bylaws, Article II, Section 2.2(b) and Article IX, Section 9.6

Text:

“No part of the net earnings of The Order shall inure to the benefit of, or be distributable to, its directors, officers, or other private persons, except that The Order 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 herein.”

Line 3 — Prohibition on Lobbying as Substantial Activity

Does your organizing document prohibit attempting to influence legislation as a substantial part of activities?

Yes.

Location: Bylaws, Article II, Section 2.2(c)

Text:

“No substantial part of the activities of The Order shall be the carrying on of propaganda or otherwise attempting to influence legislation.”

Note: The Order engages in lawful legislative advocacy — including urging Congress to fund rare disease research through the DoD CDMRP, meeting with legislative staff, and submitting regulatory comments — as a program activity within bounds. See Part VIII, Line 4(a) below. Once the IRS determination letter is received, The Order will file Form 5768 (the 501(h) election) to replace the “no substantial part” standard with a specific expenditure safe harbor.

Line 4 — Prohibition on Political Campaign Intervention

Does your organizing document prohibit participation or intervention in political campaigns on behalf of or in opposition to any candidate?

Yes.

Location: Bylaws, Article II, Section 2.2(c)

Text:

“The Order shall not participate in or intervene in any political campaign on behalf of or in opposition to any candidate for public office.”

Line 5 — Dissolution Clause

Does your organizing document contain a dissolution clause directing remaining assets to exempt purposes?

Yes.

Location: Bylaws, Article II, Section 2.3

Text:

“Upon the dissolution of The Order, assets shall be distributed for one or more exempt purposes within the meaning of Section 501(c)(3) of the Internal Revenue 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 the superior court of the county in which the principal office of The Order is located, exclusively for such purposes or to such organization or organizations, as said court shall determine, which are organized and operated exclusively for such purposes.”

**PART V — COMPENSATION AND OTHER
FINANCIAL ARRANGEMENTS**

IRS Form 1023, Part V asks about compensation paid or planned for officers, directors, trustees, key employees, and independent contractors.

Section A — Officers, Directors, Trustees, and Key Employees
Current officers and directors:

Name	Title	Avg Hrs/Week	Compensation
Sherry Kinkade	President, Founder, Director	5+	\$0

No other directors, officers, or key employees are currently seated. Additional directors are being recruited.

Is any compensation currently paid or planned for any officer, director, or trustee?

No compensation is currently paid to any person for governance service. No compensation is planned unless and until the organization grows to a scale where paid staff are necessary to deliver programs.

If compensation is paid in the future, how will it be determined?

Any future compensation paid to officers, directors, or key employees — including any Executive Director hired by the Board — will be determined through the following process, as set forth in The Order’s Conflict of Interest Policy:

1. The Board’s Compensation Committee, consisting of at least two disinterested directors not including the person whose compensation is under review, will evaluate the proposed compensation.
2. The Compensation Committee will obtain and consider comparability data — compensation paid by similarly situated rare disease nonprofit organizations for comparable services.
3. The Compensation Committee will document its deliberations and the comparability data reviewed in Board minutes.
4. The full Board will vote to approve any compensation above a threshold set by the Board.

This process is designed to satisfy the rebuttable presumption of reasonableness under IRC Section 4958 (intermediate sanctions).

Section B — Relationships Between Officers, Directors, Trustees, and Key Employees

Do any of your officers, directors, trustees, or key employees have a family relationship or business relationship with any other officer, director, trustee, or key employee?

No.

Section C — Business Transactions with Interested Persons

Has The Order entered into any transaction with any officer, director, trustee, creator, or key employee? No.

Does The Order lease property from or to any officer, director, trustee, creator, or key employee? No.

Has The Order paid any person for personal services (such as consulting) other than as compensation for services rendered as an officer, director, trustee, or key employee? No.

Section D — Independent Contractors

Has The Order paid or does it plan to pay any independent contractor \$50,000 or more?

No. The Order has not yet engaged any independent contractors. If independent contractors are engaged in the future (for example, a web developer, accountant, or legal counsel), their compensation will be disclosed on the annual Form 990 as required.

PART VIII — SPECIFIC ACTIVITIES

IRS Form 1023, Part VIII asks a series of yes/no questions about the organization's specific activities.

Line 1 — Political Campaign Intervention

Do you support or oppose candidates in political campaigns, or do you intend to do so?

No. The Order does not support or oppose any candidates for public office and will not do so. This prohibition is absolute and is codified in the Bylaws at Article II, Section 2.2(c).

Line 2 — Attempts to Influence Legislation

Do you attempt to influence legislation?

Yes, within limits permitted under Section 501(c)(3).

The Order engages in legislative advocacy as a program activity of the FLOCK & Raise a Squawk and FORGE the Standards missions. Specifically, The Order:

- Advocates to Congress for appropriations to the Department of Defense Congressionally Directed Medical Research Programs (CDMRP) for schwannomatosis research funding
- Urges patients and supporters to contact their Congressional representatives about rare disease research funding

- Submits comments to federal agencies on regulatory matters affecting schwannomatosis patients and the rare disease community
- Advocates to the Centers for Medicare and Medicaid Services (CMS) for schwannomatosis-specific clinical quality measures

Legislative advocacy is not the primary activity of The Order — it is one component of the FLOCK and FORGE missions, which together represent 55% of program activity. Upon receiving the IRS determination letter, The Order will file Form 5768 to elect the 501(h) expenditure safe harbor, providing legal clarity on permissible lobbying expenditure levels.

The Order does not engage in direct lobbying of legislative bodies as a substantial portion of its activities and will not expend resources on lobbying in excess of the 501(h) limits once elected.

Line 3 — Bingo or Gaming Activities

Do you or will you operate bingo or other gaming activities?

The Order may conduct charitable raffles, silent and live auctions, and similar fundraising events as part of the FUEL with Coin mission. All such activities will comply with applicable Washington State charitable gaming and solicitation laws.

Line 4 — Grants, Scholarships, and Other Assistance

Do you or will you make grants, loans, scholarships, or other distributions to individuals?

Yes — planned.

The Order plans to operate the SWN Fund patient access grant program, which will provide financial assistance to schwannomatosis patients who face financial barriers to accessing specialist care. Grants will cover travel, lodging, caregiver costs, and gaps in care costs after insurance for patients traveling to an NF clinic, SWN specialist, or clinical trial site. The SWN Fund grant program is planned; it has not yet been launched because the bank account has not been opened and no funds have been raised.

Selection criteria: Eligibility criteria, application process, and selection methodology are documented in the SWN Fund Patient Assistance Guidelines (separate Foundation document). Grants are awarded based on patient need, without regard to board or volunteer affiliation. Board members and officers who are schwannomatosis patients may apply; they must recuse themselves from any decision about their own application.

Anti-discrimination: Grants are available to patients regardless of schwannomatosis subtype, race, ethnicity, gender, disability status, or any other protected characteristic.

Line 5 — Fundraising

Do you have a fundraising program?

Yes.

The Order raises funds through individual donations; stock and appreciated securities donations; donated airline miles and loyalty points; gaming and merchandise revenue; peer-to-peer and crowdfunding campaigns; workplace giving and employer matching; memorial and tribute gifts; major gifts and planned giving; corporate sponsorships and industry partnerships; special events, raffles, and auctions; and grants from private foundations, government agencies, and rare disease funders.

All fundraising is conducted in compliance with Washington State charitable solicitation requirements and any other applicable state registration requirements.

Fundraising disclosure: The Order discloses all corporate, pharmaceutical, and medical industry gifts publicly in accordance with its Gift Acceptance Policy. No gift is accepted that conditions its receipt on an audit outcome or advocacy position.

Line 6 — Relationships with Other Organizations

Are you affiliated with or related to any other organization?

No formal affiliation or legal relationship currently exists.

The Order has engaged in programmatic collaboration with the following organizations and anticipates future collaboration:

- **NORD (National Organization for Rare Disorders)** — The Order is pursuing NORD fiscal sponsorship during the IRS determination period. NORD is an independent 501(c)(3) organization. The fiscal sponsorship relationship, if established, will be governed by a written agreement. It does not constitute control, ownership, or governance affiliation.
- **Children’s Tumor Foundation (CTF) NF Registry** — The Order connects patients to the CTF NF Registry (NCT01885767) as part of the FLOCK mission. This is a programmatic referral relationship; The Order does not operate or control the CTF registry.

PART X — PUBLIC CHARITY STATUS

IRS Form 1023, Part X asks you to select the public charity status under which you are seeking exemption. The Order seeks status as a public charity under Section 509(a)(1), supported by Section 170(b)(1)(A)(vi).

Selected Status: Section 509(a)(1) / Section 170(b)(1)(A)(vi)

Basis: The Order is organized to receive support from the general public, from government grants, and from a wide variety of donors — individual donors, family foundations, corporate sponsors, and government agencies. The Order does not receive support primarily from a single source, investment income, or unrelated business income. The Order expects to meet the one-third public support test under Section 170(b)(1)(A)(vi) based on its planned fundraising model.

New organization: The Order of the SWNs Foundation was incorporated in Washington State on September 17, 2026. The organization has been in existence for fewer than five years and does not yet have five years of financial data. The Order represents that it reasonably expects to meet the public support test during its first five years of operation based on:

- A fundraising model built primarily on individual small-donor giving, peer-to-peer campaigns, and employer matching programs
- Plans to pursue grants from government agencies (including NIH, DoD CDMRP, and state rare disease programs) and private foundations
- No significant reliance on investment income, unrelated business income, or single-source funding

Financial data: Attached as Part IX (Financial Data — Budget/Projections).

FORM 1023 — SCHEDULE H
Organizations Providing Grants to Individuals
The Order of the SWNs Foundation

EIN: 42-4978003 | **State:** Washington | **Date of Incorporation:** September 17, 2026 | **Prepared:** September 23, 2026

This Schedule H is filed in response to Form 1023 Part VIII, Line 4. The Order of the SWNs Foundation plans to provide grants to individual schwannomatosis patients through the SWN Fund, a designated sub-fund of the FUEL Fund. No grants have been awarded as of September 23, 2026. The bank account has not yet been opened and the SWN Fund is not yet operational.

Applicability: This Schedule is required because The Order answered *Yes* to Form 1023 Part VIII, Line 4 — The Order plans to provide grants to individuals to cover specific financial barriers that prevent schwannomatosis patients from accessing specialist care. These are patient care access grants, not scholarships or educational grants.

SECTION I — PROGRAM DESCRIPTION

1. Describe your grant program. Include the purpose of the grants, eligibility requirements, how recipients apply, who selects recipients, the amount and number of grants, and how you ensure grants are used for their intended purpose.

Program name: SWN Fund — Patient Access Grants

Purpose: The SWN Fund provides targeted grants to schwannomatosis patients to fill specific financial gaps that prevent them from accessing qualified specialist care. Schwannomatosis is a rare disorder with an average diagnostic delay of 16.7 years (Merker et al., 2022). Even after diagnosis, many patients cannot afford the travel, lodging, and ancillary costs required to reach one of the few specialists in the country qualified to manage their condition. The SWN Fund does not replace medical insurance or provide general income support. It covers specific, documented out-of-pocket expenses directly related to accessing schwannomatosis specialist care.

Covered expenses: Grants may cover any of the following when directly related to accessing SWN specialist care:

- Transportation to specialist appointments (airfare, train, bus, mileage reimbursement at IRS rate)
- Lodging near treatment centers or during inpatient stays
- Caregiver or companion travel and lodging when the patient's condition requires accompaniment
- Medical equipment, assistive devices, or supplies not covered by insurance and directly related to SWN care
- Out-of-pocket co-pays, deductibles, or cost-sharing obligations for SWN specialist visits not otherwise subsidized

What is not covered: The SWN Fund does not cover ongoing living expenses, food, general transportation unrelated to specialist care, cosmetic procedures, experimental treatments not supervised by a qualified specialist, or any expense for which the patient has received or is eligible to receive reimbursement from another source.

2. What are the eligibility requirements?

To be eligible for a SWN Fund grant, an applicant must:

- Have a documented diagnosis of schwannomatosis (any subtype, including SMARCB1-SWN, LZTR1-SWN, SMARCE1-SWN, DGCR8-SWN, gene-negative SWN-NEC, unclassified SWN-NOS, and NF2-related schwannomatosis NF2-SWN) or have a pending diagnosis supported by clinical evidence and a referral to a specialist
- Demonstrate a specific financial need for the requested expense — applicants are not required to disclose total income but must show that the requested expense is a genuine barrier to care access
- Be a resident of the United States at the time of application
- Submit documentation of the expense (itemized estimates, invoices, or receipts)
- Not have received reimbursement or be eligible for reimbursement for the same expense from another source

No applicant is denied on the basis of race, color, national origin, sex, disability, age, religion, sexual orientation, gender identity, or schwannomatosis subtype. Patients without a confirmed genetic mutation (SWN-NEC) are expressly eligible; the Fund exists specifically to serve the patients with the least diagnostic and clinical infrastructure.

Board members, officers, and volunteers of The Order who have schwannomatosis may apply for SWN Fund grants. Any such applicant must recuse themselves from all decisions regarding their own application, as required by the Conflict of Interest Policy.

3. How do recipients apply?

Applicants submit a written application to The Order's designated grant contact (initially the Executive Director/Founder; subsequently the Grant Review Committee). The application includes:

- A brief description of the applicant's diagnosis and care situation
- A description of the specific expense for which a grant is requested
- Documentation of the expense (estimate, invoice, or receipt)
- A statement confirming no other reimbursement source is available for the expense

Applications are accepted on a rolling basis as funds are available. The Order will publish the application process on its public website once the SWN Fund is operational.

4. Who selects recipients?

Year 1–2 (pre-operational / early operations): The Executive Director/Founder reviews and approves applications. No grant exceeding \$500 may be approved by a single individual without a second review by a Board member.

Year 2 onward: The Board of Directors will establish a Grant Review Committee consisting of at least two individuals, at least one of whom is a Board member. The Committee will review applications against the eligibility criteria and approve, deny, or modify grant requests. All Committee members are subject to the Conflict of Interest Policy.

Final grant awards are documented in writing and reported in The Order's annual report and Form 990 filing.

5. What is the amount of grants awarded and how many recipients do you expect annually?

Year	Estimated Recipients	Estimated Total Grants	Typical Grant Range
2026 (partial)	0	\$0	N/A — fund not yet operational
2027	0	\$0	N/A — fund not yet operational
2028	3–10	\$5,000	\$250–\$2,500 per grant
2029 (Year 3)	10–25	\$15,000	\$250–\$2,500 per grant

Grant amounts are determined by the documented cost of the specific expense, subject to the available balance of the SWN Fund. Grants are not awarded as a fixed stipend; they are tied to a specific documented expense.

6. How do you ensure grants are used for their intended purpose?

The Order uses the following controls to ensure SWN Fund grants are used for their stated purpose:

- **Direct vendor payment where possible:** For travel and lodging, The Order will pay vendors (airlines, hotels, car rental agencies) directly on behalf of the recipient wherever logistically feasible, eliminating the possibility of the funds being diverted.
- **Receipt-based reimbursement:** When direct payment is not possible, grants are disbursed as reimbursements upon submission of receipts or paid invoices documenting the specific expense.
- **Pre-approval for prospective expenses:** For future expenses (e.g., an upcoming appointment), The Order approves the grant before the expense occurs and issues payment or commits to reimbursement upon receipt submission.
- **No cash disbursements:** The Order does not issue cash grants. All payments are made by check or electronic transfer to a vendor or directly to the recipient's verified account upon receipt submission.

- **Annual reporting:** All SWN Fund grants are recorded in The Order's books and reported in the annual Form 990 as grants to individuals. The annual report published on The Order's website will describe the SWN Fund's activities and aggregate grant totals for the year.

SECTION II — EDUCATIONAL GRANTS

7. Are your grants for study at an educational institution, or for educational purposes?

No. SWN Fund grants are patient care access grants, not educational grants or scholarships. They do not fund tuition, course fees, textbooks, or any program of academic study. They fund specific out-of-pocket costs that prevent patients from reaching specialist medical care.

8. Do you provide grants for travel, study, or other similar purposes where the grant is for an educational or research purpose?

No. Travel grants from the SWN Fund are for patients traveling to medical appointments with qualified schwannomatosis specialists. The purpose is care access, not education or research participation. Recipients are not required to produce educational or research outputs.

Separately, The Order may in the future support schwannomatosis patients who participate as consumer reviewers in federal research grant programs (e.g., DoD CDMRP). Any such support would be reviewed under the Gift Acceptance Policy and Conflict of Interest Policy at that time and would not be funded through the SWN Fund.

SECTION III — RELATIONSHIP TO COMPENSATION

9. Is the grant program a substitute for compensation?

No. The SWN Fund is open to any eligible schwannomatosis patient regardless of their relationship to The Order. Grants are not tied to service, employment, volunteering, or any contribution to The Order. A Board member or volunteer who has schwannomatosis may apply on the same terms as any member of the public. The SWN Fund is a charitable assistance program, not a compensation or benefit program.

10. Do recipients have to be employees of The Order or related organizations?

No. Recipients are members of the general schwannomatosis patient community. There is no requirement that a recipient have any relationship to The Order. The only eligibility requirements are the diagnosis/clinical criteria and the financial need for the specific expense, as described in Section I above.

SECTION IV — EMERGENCY AND HARDSHIP GRANTS

11. Do you make emergency or individual hardship grants?

Yes, in limited circumstances. The Order may provide expedited review for grant applications involving time-sensitive care situations — for example, a patient who has received a same-week specialist appointment but cannot afford the transportation cost on short notice. The eligibility criteria do not change for expedited applications; the timeline for review is compressed. Expedited grants are still subject to the same documentation requirements and oversight controls described in Section I.

The Order does not provide general hardship grants for ongoing living expenses, housing, or income support. All grants are tied to a specific, documented expense directly related to SWN specialist care access.

SECTION V — ANTI-DISCRIMINATION AND EQUAL ACCESS

12. Describe your non-discrimination policy for the grant program.

The SWN Fund is available to all schwannomatosis patients without regard to race, color, national origin, sex, disability, age, religion, sexual orientation, gender identity, or schwannomatosis subtype. The Order's non-discrimination commitment is stated in its Articles of Incorporation, Bylaws (Article II, Section 2.2(e)), and Code of Conduct.

The Order expressly includes patients without a confirmed genetic mutation (SWN-NEC — gene-negative schwannomatosis) and patients with unclassified schwannomatosis (SWN-NOS) as eligible applicants. These patients are often the most underserved within the already rare schwannomatosis population, and the SWN Fund is specifically designed to reach them.

SECTION VI — CURRENT STATUS

13. Has The Order awarded any grants as of the date of this application?

No. As of September 23, 2026, The Order of the SWNs Foundation has not awarded any grants. The organization was incorporated on September 17, 2026. The bank account has not yet been opened and the SWN Fund is not yet operational. The grant program described in this Schedule H reflects The Order's planned activities upon becoming operational.

The Order expects to begin receiving donations and open the bank account after receiving the IRS determination letter or through NORD fiscal sponsorship, whichever comes first. The SWN Fund will not begin accepting applications or awarding grants until adequate funds are on hand and the Grant Review procedures described in Section I are formally adopted by the Board.

FORM 1023 — PART IV

NARRATIVE DESCRIPTION OF ACTIVITIES

The Order of the SWNs Foundation

EIN: 42-4978003 | **State of Incorporation:** Washington | **Date of Incorporation:** September 17, 2026

OVERVIEW

The Order of the SWNs Foundation is a Washington State nonprofit corporation organized exclusively for charitable, educational, and scientific purposes within the meaning of Section 501(c)(3) of the Internal Revenue Code. The Order's work addresses a documented, measurable failure in the medical care of schwannomatosis patients.

Schwannomatosis (ICD-10: Q85.03) is a rare genetic disorder causing tumors throughout the nervous system. Schwannomatosis encompasses multiple subtypes: SMARCB1-related (SWN-SMARCB1), LZTR1-related (SWN-LZTR1), SMARCE1-related (SWN-SMARCE1), DGCR8-related (SWN-DGCR8), NF2-related (NF2-SWN), gene-negative (Schwannomatosis-NEC), and unclassified (Schwannomatosis-NOS). The Order's programs serve patients across all subtypes. The Order's primary patient-finding resources are directed toward the subtypes with the greatest documented diagnostic gap and least established clinical infrastructure: SWN-SMARCB1, SWN-LZTR1, SWN-SMARCE1, SWN-DGCR8, SWN-NEC, and SWN-NOS. NF2-SWN patients have access to an established clinical network and dedicated advocacy organizations that the other subtypes largely do not; NF2-SWN patients are welcome in all of The Order's programs and community spaces. A 2022 peer-reviewed study published in the *American Journal of Medical Genetics* (Merker et al., PMID 35678462) measured the following outcomes in a cohort of schwannomatosis patients: 36% received at least one incorrect diagnosis; the median time from first symptom to correct diagnosis was 16.7 years; the median number of treating providers before correct diagnosis was 5. These are not outliers — they are the expected outcome of a medical system that lacks the awareness, clinical tools, and accountability structures needed to identify and correctly treat this population.

The Order exists to close that gap. It pursues that goal through four interconnected programs:

- **FIND the SWNs — The Mission to Find the Lost SWNs** (patient discovery and public awareness)
- **FUEL with Coin — The Mission to FUEL with Coin** (financial infrastructure; comprising the FUEL Fund as master organizational fund and three designated sub-funds: the SWN Fund for patient access grants, the Squawk Fund for community and advocacy, and the Standards Fund for clinical accountability and education)
- **FLOCK & Raise a Squawk — The Mission to Flock & Raise a Squawk** (community building, research participation, and patient advocacy)
- **FORGE the Standards — The Mission to Forge the Standards** (clinical accountability and medical education)

Each program is described in detail below.

The Order was incorporated in Washington State on September 17, 2026. Several of The Order’s educational programs were developed and made publicly available prior to formal incorporation — including the orderoftheswns.com website, the Flight of the SWN awareness game, and the patient community hub. These activities were conducted as pre-incorporation development work by the Founder and were carried forward into the incorporated entity. No donations were solicited or accepted prior to incorporation, and no tax-deductible donations have been accepted pending receipt of the IRS determination letter. Activities described as “present” reflect work underway at the time of this filing. Activities described as “planned” are on The Order’s roadmap and are expected to begin within the first two years of operation.

PROGRAM 1: FIND THE SWNS — THE MISSION TO FIND THE LOST SWNS

Percentage of total activities: approximately 25%

Purpose: The FIND the SWNs program is The Order’s patient discovery and public awareness mission. Its goal is to identify schwannomatosis patients who do not yet know what they have — patients who are in waiting rooms, already seeking care, already in medical records, but lost because no treating provider has yet recognized the pattern.

Activities (including but not limited to):

Patient Awareness Flyer Campaign (present — digital deployment active; physical clinic placement planned):

The Order has developed an awareness flyer titled “Are You a SWN?” designed to reach patients on social media, in chronic pain clinics, neurology waiting rooms, and spine care settings. The flyer presents the defining symptom cluster of schwannomatosis (multiple tumors, chronic pain, neurological symptoms) in plain language and directs patients to The Order’s website and to schwannomatosis specialists and SWN expert resources. The flyer is complete and currently available on The Order’s website. Physical placement in clinic waiting rooms will be planned future phases contingent on available funding. *Beneficiaries: undiagnosed schwannomatosis patients and their families.*

Flight of the SWN — Patient Awareness Game (present):

The Order has developed and deployed Flight of the SWN, an online educational game available free of charge at orderoftheswns.com. The game places players in the role of a patient navigating the diagnostic journey for schwannomatosis, experiencing the same cognitive failure points — anchoring bias, availability bias, pattern-matching without evidence — that produce the 16.7-year average delay documented in the medical literature. The game’s purpose is patient education: players learn the name and nature of schwannomatosis, the diagnostic criteria, the barriers to correct diagnosis, and the path to an NF specialist. The game is freely playable without payment. Optional in-game donations will support The Order’s FUEL Fund once the bank account is established and donations are open. The game is available through The Order’s website and distributed through patient community platforms and partnership with NF advocacy organizations. Social media campaigns are a planned future distribution channel. *Beneficiaries: undiagnosed and newly diagnosed schwannomatosis patients; caregivers; members of the public.*

Patient Community Outreach (present):

The Order’s founder and volunteers conduct outreach in online patient communities — including Inspire Health Network, Facebook chronic pain groups, and schwannomatosis-specific support communities — to reach individuals who may have undiagnosed schwannomatosis. Outreach materials present diagnostic information derived from published international consensus criteria (Plotkin et al., *Genetics in Medicine*, 2022) and direct interested individuals to The Order’s resources and to specialist referral pathways. *Beneficiaries: patients in chronic pain and neurological communities who may have undiagnosed schwannomatosis.*

Patient Survey and Database (present):

The Order conducts a voluntary patient survey to identify individuals with schwannomatosis or suspected schwannomatosis who lack access to specialist care. Survey responses are used to assess unmet care needs and to connect patients to appropriate schwannomatosis specialist resources. No personally identifying information is shared outside The Order. *Beneficiaries:* schwannomatosis patients with unmet care needs.

Additional FIND the SWNs activities: The Order may conduct or support any other program, activity, partnership, or initiative reasonably designed to identify schwannomatosis patients, reduce diagnostic delay, increase public or clinician awareness of schwannomatosis, or connect individuals to appropriate specialist care and community resources. The activities listed above are illustrative, not exhaustive.

How this activity furthers exempt purposes: The FIND the SWNs program is educational (it teaches patients and the public about a poorly understood rare disease and the diagnostic criteria needed to identify it) and charitable (it reduces barriers to correct diagnosis for a population experiencing documented, systematic medical failure). Every patient reached by the FIND program who subsequently connects to specialist care represents a direct reduction in the harm produced by diagnostic delay.

PROGRAM 2: FUEL WITH COIN — THE MISSION TO FUEL WITH COIN

Percentage of total activities: approximately 20%

Purpose: The FUEL with Coin program encompasses The Order's financial infrastructure and its charitable patient assistance activities. The FUEL Fund is The Order's master organizational fund — receiving all revenue and distributing down to three designated sub-funds: the SWN Fund (patient access grants), the Squawk Fund (community building, advocacy, and conference presence), and the Standards Fund (clinical accountability, physician education, EHR development, and medical curriculum advocacy). Each sub-fund is maintained separately. Operational costs not attributable to a specific sub-fund are covered directly by the FUEL Fund.

Background on the gap this program addresses: Expert care for schwannomatosis is concentrated at a small number of academic medical centers across the United States. Many schwannomatosis patients — particularly those in rural areas or regions without an NF Clinic — must travel substantial distances to reach appropriate specialists. A round trip for patient and caregiver to a major academic NF center costs ,at this time, between \$2,465 and \$6,330 depending on origin city, including flights, hotel, ground transportation, and meals. Existing patient assistance programs (Angel Flight, PAN Foundation, HealthWell Foundation, etc.) use income thresholds designed for patients near or below the poverty line. They leave a documented gap: patients whose income disqualifies them from assistance but for whom several thousand dollars per trip, multiplied across multiple specialist visits and clinical trial visits per year, is genuinely unaffordable. The SWN Fund addresses that gap.

Activities (including but not limited to):

Patient Travel and Access Grants (planned — to begin in year one of operation):

The Order will provide grants to schwannomatosis patients who meet documented eligibility criteria to cover travel, lodging, and caregiver costs associated with traveling to an NF clinic, NF specialist, or SWN expert. Eligibility criteria are based on: geographic distance to the nearest appropriate NF Clinic or SWN expert; frequency of required visits (clinical trial protocol, annual surveillance schedule); and the ratio of travel cost to disposable income after medical expenses. All grants cover both the patient and one accompanying caregiver — The Order recognizes that for patients with chronic pain, neurological symptoms, or post-procedure recovery needs, unaccompanied travel is not a realistic expectation. Grant applications will be reviewed by The Order's founder or designated volunteers. Grant awards will be reported in The Order's annual report. Grant eligibility criteria are documented and applied consistently; all awards are subject to The Order's conflict of interest policy. Board members, officers, and volunteers who are schwannomatosis patients may apply for patient assistance grants through the same process as any other applicant; any board member or officer must recuse from any vote or decision regarding their own application. Organizational travel expenses for board members and volunteers acting in their capacity as Order representatives — such as attendance at conferences — are reimbursed as program expenses from the applicable fund and are not patient assistance grants. *Beneficiaries: schwannomatosis patients of all subtypes facing documented financial and geographic barriers to specialist care.*

Research Funding Advocacy (planned):

The Order plans to advocate for increased research investment in schwannomatosis — including advocacy to the Department of Defense Congressionally Directed Medical Research Programs (CDMRP), the National Institutes of Health rare disease programs, and private foundations — with priority given to research areas where funding has been discontinued despite scientific validation, and to studies addressing the lesser-known subtypes most underrepresented in the current research literature. The Order will use its patient community infrastructure to support researcher access to patients for enrollment and patient-reported outcomes collection and will amplify researcher funding requests through its advocacy channels. *Beneficiaries: schwannomatosis patients as a population, through advancement of research toward diagnosis, treatment, and cure.*

Note on fundraising operations:

The Order raises funds through the FUEL Fund — its master organizational fund — via individual donations; stock and appreciated securities donations; donated airline miles and loyalty points; gaming and merchandise revenue including optional donations through the Flight of the SWN game; raffles, auctions, and special events; peer-to-peer and crowdfunding campaigns; workplace giving and employer matching programs; memorial and tribute gifts; major gifts and planned giving; corporate sponsorships and industry partnerships (disclosed publicly); and grants from private foundations, government agencies including DoD CDMRP and NIH rare disease programs, and rare disease funders. During the IRS 501(c)(3) determination period, The Order will pursue NORD fiscal sponsorship as the bridge that enables tax-deductible donations before the determination letter is received. The SWN Fund, Squawk Fund, and Standards Fund are designated sub-funds of the FUEL Fund, each receiving allocated distributions from the master fund. Fundraising operations serve the exempt programs described in this narrative; they are not themselves a program activity. None of the four funds is currently operational; the bank account has not been opened.

Additional FUEL with Coin activities: The Order may pursue any other lawful fundraising method, patient assistance program, or financial stewardship activity in support of its exempt purposes — including additional grant programs, emergency assistance funds, in-kind support programs, and any other charitable assistance to schwannomatosis patients that falls within the scope of the FUEL Fund and its sub-funds. The activities listed above are illustrative, not exhaustive.

How this activity furthers exempt purposes: Direct patient assistance is a charitable activity under Section 501(c)(3). The SWN Fund removes documented financial barriers to medical care for a defined class of individuals (schwannomatosis patients) who face an identifiable, specific hardship (geographic distance to rare disease specialists and SWN experts combined with inadequate coverage by existing assistance programs).

PROGRAM 3: FLOCK & RAISE A SQUAWK — COMMUNITY BUILDING AND ADVOCACY

Percentage of total activities: approximately 20%

Purpose: The FLOCK & Raise a Squawk program is The Order's community and advocacy mission. Schwannomatosis patients are isolated by definition — scattered across geographic regions, subtypes, and diagnostic histories. Isolation compounds the harm of diagnostic delay: patients who do not know others with their condition have fewer resources for navigating care, less collective voice in research priorities, and less capacity to participate in the clinical trials and registries that advance the science. FLOCK builds the infrastructure that ends that isolation.

Activities (including but not limited to):

Round Table — Ongoing Community Conversation (present):

The Order hosts a recurring open community conversation — the Round Table — for schwannomatosis patients, family members, caregivers, and advocates. The Round Table is held via video conference and open to all. It provides a space for peer support, information exchange about current research, and connection to The Order's programs and resources. Clinicians and researchers are welcome participants — the Round Table is designed to facilitate direct dialogue between the patient community and the medical and scientific community. The Order's website at orderoftheswms.com hosts a community hub and Discord server where ongoing conversation occurs between Round Table sessions.

Beneficiaries: schwannomatosis patients, their families, caregivers, and the clinicians and researchers who serve them.

NF Registry Enrollment Outreach (present):

The Order conducts outreach to connect schwannomatosis patients with the Neurofibromatosis Registry ([clinicaltrials.gov: NCT01885767](https://clinicaltrials.gov/ct2/show/study/NCT01885767)), a patient-reported longitudinal registry maintained through the Children's Tumor Foundation. Registry enrollment gives patients a formal voice in the research record and enables researchers to identify and contact eligible participants for clinical studies. *Beneficiaries: schwannomatosis patients who wish to contribute to research.*

Clinical Trial Awareness (present):

The Order maintains and disseminates current information about active clinical trials enrolling schwannomatosis patients — including the STARFISH trial (NCT05684692, PI: Dr. Scott Plotkin, Massachusetts General Hospital), which studies pain management in all schwannomatosis subtypes. Trial awareness outreach is conducted through The Order’s website, the community hub, and direct outreach to newly connected patients. *Beneficiaries: schwannomatosis patients who may be eligible for clinical research participation.*

Conference and Summit Presence (planned):

The Order plans to establish a presence at the annual NF Conference organized by the Children’s Tumor Foundation, the NF Summit, and other scientific and clinical conferences where schwannomatosis research and clinical standards are discussed. The Order’s conference presence serves to amplify the SWN patient community’s voice in scientific settings, to connect patients to researchers and clinicians, and to represent The Order’s programs to potential partners, credentialing bodies, and funders. Conference and community advocacy costs are supported by the Squawk Fund. *Beneficiaries: schwannomatosis patients, represented in settings where their interests would otherwise be unvoiced.*

Additional FLOCK & Raise a Squawk activities: The Order may conduct or support any other program, activity, partnership, or initiative reasonably designed to connect, support, educate, or mobilize the schwannomatosis patient community — including additional community events, patient support programs, advocacy campaigns, legislative engagement, and partnership activities with rare disease organizations and NF advocacy groups. The activities listed above are illustrative, not exhaustive.

How this activity furthers exempt purposes: Community-building for a defined class of individuals facing an identified hardship is a charitable activity. Advocacy for improved medical standards and research investment on behalf of a patient population is educational. The FLOCK program serves the interests of schwannomatosis patients as a class, not any individual, and does not engage in political campaign activity or substantial legislative lobbying.

PROGRAM 4: FORGE THE STANDARDS — CLINICAL ACCOUNTABILITY AND MEDICAL EDUCATION

Percentage of total activities: approximately 35%

Purpose: FORGE the Standards is The Order’s clinical accountability and medical education mission. Published diagnostic criteria for schwannomatosis (Plotkin et al., *Genetics in Medicine*, 2022) and international clinical practice guidelines for diagnosis, treatment, management, and surveillance (ERN GENTURIS, *European Journal of Human Genetics*, 2022) exist and are available to every treating provider. What does not yet exist is a consistent, enforceable connection between those published standards and what happens in the clinical encounter — from the radiologist at a local clinic who fails to recognize a schwannoma on imaging and closes the record without follow-up, to the neurologist at a regional hospital who tells a patient they have never seen anything like it and recommends a psychiatric evaluation, to the physician at an NF Clinic who holds themselves out as treating schwannomatosis but whose expertise does not extend meaningfully beyond the most common form of the disease. These are not edge cases. They are the documented pattern.

The 36% misdiagnosis rate and 16.7-year average diagnostic delay documented in Merker et al. 2022 are products of specific, named failures in clinical reasoning: anchoring bias (locking onto a first diagnosis without updating against new evidence); availability bias (defaulting to the most common diagnosis regardless of fit); base rate neglect (treating rarity as grounds for dismissal); confirmation bias (building a clinical record that cements an incorrect diagnosis across years); pattern-matching without evidence (bypassing formal diagnostic criteria); and radiological blindspot (failure by imaging specialists to recognize NF-spectrum tumors). FORGE treats these cognitive failure points as the root pathology and treats clinical standards as the treatment protocol.

Activities (including but not limited to):

Clinical Provider Evaluation Framework (planned):

The Order will develop an evaluation methodology for assessing whether clinical providers and facilities claiming schwannomatosis expertise are providing care consistent with published clinical standards. The framework will use publicly available data sources — including CMS Medicare Physician and Outpatient claims data, Open Payments data, provider-published materials, and patient-reported experience — to document patterns of care delivery at facilities and individual physicians who hold themselves out as schwannomatosis specialists. Each finding will be cited to a published clinical standard. The Order will not use evaluation findings to target individual providers for harassment or to provide legal advice. The Order expects to complete the evaluation framework and begin deployment within the first two years of operation, producing publishable findings available to patients, credentialing bodies, and the public. Clinical accountability activities are supported by the Standards Fund. *Beneficiaries: schwannomatosis patients as a population; credentialing bodies and payers who rely on accurate information about specialty care quality.*

SWN Specialist Directory and Profile Database (present):

The Order maintains and continuously updates a database of clinics and individual physicians who claim schwannomatosis expertise — documenting what they say publicly about their capabilities, which subtypes they address, their published research, and patient-reported experience. This database is not limited to any single clinic network; it includes any clinic or individual physician who claims SWN expertise, regardless of institutional affiliation. The public-facing output of this database is The Order’s SWN specialist directory at theorderoftheswns.org/clinics. This database informs The Order’s evaluation work and is used to direct patient referrals to appropriately qualified specialists. *Beneficiaries: schwannomatosis patients seeking specialist referral; the medical community.*

Physician Education — Two-Tier Clinical Reference (planned):

The Order is developing a two-tier physician education kit. Tier 1 is a full clinical reference for neuro-oncologists and NF/SWN specialists covering current diagnostic criteria, treatment options, clinical trial availability, and referral protocols for all schwannomatosis subtypes. Tier 2 is a shorter recognize-and-refer card for general neurologists and other non-specialist providers who are likely to encounter schwannomatosis patients before specialist involvement. Both materials are derived from published, peer-reviewed sources. The Order intends to make both materials freely available and to distribute them through NF/SWN advocacy organization partnerships, conference presence, and direct outreach to clinic medical directors. *Beneficiaries: schwannomatosis patients, through improved clinician awareness; the general medical community.*

EHR Clinical Decision Support (planned):

The Order is developing a specification for an Electronic Health Record clinical decision support alert — an Epic Best Practice Advisory (BPA) and parallel FHIR CDS Hooks specification — that fires when two or more ICD-10 codes consistent with schwannomatosis (schwannoma diagnoses) appear in a single patient record. The alert would prompt the treating provider to consider schwannomatosis evaluation and provide a direct link to the NF/SWN Clinic finder. This alert, if adopted, would systematically surface patients at the point of clinical encounter regardless of whether the treating provider is familiar with schwannomatosis. The Order intends to present the specification to Epic's App Orchard program and to clinical informaticists at NF Clinic partner institutions. *Beneficiaries: schwannomatosis patients who would otherwise remain undiagnosed within existing EHR-connected care systems.*

Medical School and Residency Curriculum Advocacy (planned):

The Order plans to advocate for the inclusion of NF/SWN-spectrum disease — including schwannomatosis in all its subtypes — in medical school and residency training curricula. This advocacy will be directed at the Association of American Medical Colleges (AAMC) and the Accreditation Council for Graduate Medical Education (ACGME) and conducted in partnership with NF/SWN clinical experts including members of the Children's Tumor Foundation's Clinical Care Advisory Board. The Order's goal is not to train every physician as an NF specialist, but to ensure that every physician learns to recognize the diagnostic pattern and respond correctly: refer to an NF Clinic. *Beneficiaries: future schwannomatosis patients, through reduced diagnostic delay.*

Interstate Telehealth Licensing Advocacy (planned):

The Order plans to advocate for schwannomatosis specialists at NF Clinic Network centers to join the Interstate Medical Licensure Compact (IMLC), enabling cross-state telemedicine visits without individual state license applications. Both Massachusetts (home of Massachusetts General Hospital, a leading SWN center) and Washington State (The Order's home state) are IMLC member states. Successful telemedicine licensing would allow patients in states without NF Clinics to receive specialist consultation remotely, reducing or eliminating the travel burden documented in the SWN Fund program description above. Advocacy will be directed to NF Clinic medical directors and to the Children's Tumor Foundation's Clinical Care Advisory Board. *Beneficiaries: schwannomatosis patients in states without NF Clinics.*

Additional FORGE the Standards activities: The Order may conduct or support any other program, activity, publication, partnership, or initiative reasonably designed to improve the quality of clinical care for schwannomatosis patients, advance evidence-based clinical standards, hold clinical providers accountable to those standards, or reform the structures — educational, regulatory, technological, or financial — that perpetuate diagnostic delay. The activities listed above are illustrative, not exhaustive.

How this activity furthers exempt purposes: Clinical accountability work and medical education are educational activities under Section 501(c)(3). The FORGE program advances public knowledge of a documented medical problem (diagnostic failure in schwannomatosis care), educates the medical community through peer-reviewed, evidence-based materials, and advocates for structural reforms that serve the public interest. The program does not generate private benefit for The Order’s officers, directors, or founders. Audit findings are based on publicly available data and are cited to published standards.

SUMMARY TABLE

Program	Type	Status	% of Activities
FIND the SWNs — The Mission to Find the Lost SWNs	Educational / Charitable	Present	25%
FUEL with Coin — The Mission to FUEL with Coin	Charitable	Framework established; all four funds not yet operational	20%
FLOCK & Raise a Squawk — The Mission to Flock & Raise a Squawk	Charitable / Educational	Present	20%
FORGE the Standards — The Mission to Forge the Standards	Educational	Present — specialist directory and profile database active; evaluation framework planned	35%

CONFLICT OF INTEREST POLICY

The Order of the SWNs Foundation

This policy is modeled on the IRS sample conflict of interest policy (Form 1023, Appendix A) and includes provisions specific to The Order's pharmaceutical disclosure requirements and FORGE audit integrity.

ARTICLE I — PURPOSE

The purpose of this conflict of interest policy is to protect the interests of The Order of the SWNs Foundation when it is contemplating entering into a transaction or arrangement that might benefit the private interests of an officer or director of The Order or might result in a possible excess benefit transaction. This policy is intended to supplement, but not replace, any applicable state and federal laws governing conflict of interest applicable to nonprofit and charitable organizations.

ARTICLE II — DEFINITIONS

SECTION 2.1 — INTERESTED PERSON

Any director, principal officer, or member of a committee with governing board-delegated powers who has a direct or indirect financial interest, as defined below, is an interested person.

SECTION 2.2 — FINANCIAL INTEREST

A person has a financial interest if the person has, directly or indirectly, through business, investment, or family:

- (a) an ownership or investment interest in any entity with which The Order has a transaction or arrangement;

(b) a compensation arrangement with The Order or with any entity or individual with which The Order has a transaction or arrangement; or

(c) a potential ownership or investment interest in, or compensation arrangement with, any entity or individual with which The Order is negotiating a transaction or arrangement.

Compensation includes direct and indirect remuneration as well as gifts or favors that are not insubstantial.

A financial interest is not necessarily a conflict of interest. Under Section 3.2, a person who has a financial interest may have a conflict of interest only if the appropriate governing board or committee decides that a conflict of interest exists.

SECTION 2.3 — COVERED PERSONS

This policy applies to all members of the Board of Directors, all officers of The Order, all members of the Medical Advisory Board (The Consular Circle), and all members of any committee to which the Board has delegated decision-making authority.

Members of the Patient Advisory Council (The Pathfinders) and Volunteer Council (The Bevy of SWNs) are not Covered Persons under this policy unless they are also serving in a capacity listed above. However, The Order encourages all advisors and volunteers to disclose any potential conflicts voluntarily.

SECTION 2.4 — WHAT IS NOT A CONFLICT OF INTEREST

The following are not conflicts of interest under this policy:

(a) Being a schwannomatosis patient — A director, officer, or advisor who is themselves a schwannomatosis patient does not have a conflict of interest with respect to The Order's programs and mission by virtue of being a patient. The Order was established to serve SWN patients. Patient directors serve this mission, not their personal interest, when they advance The Order's programs.

(b) Receiving patient assistance grants — A director, officer, or advisor who applies for and receives a patient assistance grant from the SWN Fund is not in conflict of interest provided: (i) the patient assistance program is open to all qualifying patients; (ii) the individual recused themselves from any decision about their own application; and (iii) the grant meets the criteria applied to all applicants.

(c) Being a clinician, researcher, or academic — An MAB member who has an institutional affiliation with a hospital, university, or research program is not in conflict with respect to Order advisory activities, provided any specific financial relationships are disclosed under Article III.

ARTICLE III — DISCLOSURE PROCEDURES

SECTION 3.1 — DUTY TO DISCLOSE

In connection with any actual or possible conflict of interest, an interested person must disclose the existence of the financial interest and be given the opportunity to disclose all material facts to the directors and members of committees with governing board-delegated powers considering the proposed transaction or arrangement.

SECTION 3.2 — TIMING OF DISCLOSURE

Disclosure must occur:

(a) At the time the interest arises — if a Covered Person becomes aware of a potential conflict in connection with a pending transaction, they must disclose immediately, before any vote or decision is taken;

(b) At each annual disclosure — every Covered Person must complete and submit an Annual Disclosure Statement (see Exhibit A) at the beginning of each calendar year and within thirty (30) days of joining the Board, MAB, or any committee; and

(c) Whenever a new relationship arises — if a Covered Person enters into a new compensated relationship, ownership interest, or similar arrangement that could create a conflict, they must disclose it within thirty (30) days of the relationship beginning.

SECTION 3.3 — PHARMACEUTICAL AND MEDICAL INDUSTRY DISCLOSURE

Given The Order's FORGE the Standards mission, Covered Persons must disclose all compensated relationships with pharmaceutical companies, medical device companies, NF clinical programs, and NF clinical research sponsors, including:

- Speaking fees, honoraria, or consulting fees, regardless of amount
- Research funding, grants, or salary support
- Equity interests, stock options, or investment interests
- Advisory board or paid consulting roles

Pharmaceutical and medical industry disclosures are not disqualifying. Failure to disclose is disqualifying.

ARTICLE IV — DETERMINING WHETHER A CONFLICT EXISTS

After disclosure of the financial interest and all material facts, and after any discussion with the interested person, the interested person shall leave the governing board or committee meeting while the determination of a conflict of interest is discussed and voted upon. The remaining board or committee members shall decide if a conflict of interest exists.

ARTICLE V — PROCEDURES FOR ADDRESSING THE CONFLICT

The Order maintains a four-fund structure: the **FUEL Fund** (master organizational fund, receives all revenue and donations) distributes to three sub-funds — the **SWN Fund** (patient focused grants), the **Squawk Fund** (community building and advocacy), and the **Standards Fund** (clinical accountability and education). The conflict of interest procedures in this Article apply to all fund-related decisions. Sections 5.3 and 5.4 provide additional protections specific to FORGE the Standards audit work and SWN Fund patient grant administration respectively.

SECTION 5.1 — RECUSAL AND ABSTENTION

An interested person may make a presentation at the governing board or committee meeting, but after the presentation, they shall leave the meeting and shall not participate in the final deliberation or vote on the matter, giving rise to the conflict of interest. However, the Chairperson of the governing board or committee shall, if appropriate, appoint a disinterested person or committee to investigate alternatives to the proposed transaction or arrangement.

SECTION 5.2 — DETERMINING WHETHER THE TRANSACTION IS IN THE ORDER'S INTEREST

After exercising due diligence, the governing board or committee shall determine whether The Order can obtain, with reasonable efforts, a more advantageous transaction or arrangement from a person or entity that would not give rise to a conflict of interest.

If a more advantageous transaction or arrangement is not reasonably possible under circumstances not producing a conflict of interest, the governing board or committee shall determine by a majority vote of the disinterested directors whether the transaction or arrangement is in The Order's best interest, for its own benefit, and whether it is fair and reasonable.

SECTION 5.3 — FORGE AUDIT INTEGRITY — ENHANCED RECUSAL

For decisions related to the FORGE the Standards audit mission — including selection of entities to audit, development of audit methodology, review of audit findings, and publication of audit results — any Covered Person who has a current or recent (within three years) compensated relationship with an entity under review must recuse themselves from all discussions and decisions related to that entity's audit.

SECTION 5.4 — SWN FUND GRANT INTEGRITY — CATEGORICAL EXCLUSION

No person who has a current financial relationship with any pharmaceutical company, medical device company, clinical research sponsor, or biotechnology company — including employment, consulting arrangements, speaking fees, advisory board roles, equity interests, or any other compensated relationship, regardless of whether that company has any connection to the specific grant application under review — may participate in any capacity in the review, scoring, approval, denial, or administration of SWN Fund patient assistance grants.

This exclusion is categorical and structural, not case-by-case. It applies even when the individual's employer has no product or trial relevant to the specific applicant. The integrity of the patient grant program depends on grant decisions being made entirely free of pharmaceutical industry influence — not merely free of the specific conflict presented by any one company. Industry partners and their representatives are valued contributors to The Order's programs in other capacities; grant administration is not one of them.

Any person subject to this exclusion who is currently serving in a grant review role must immediately disclose that relationship and step down from that role. Failure to disclose a pharmaceutical or device industry relationship while serving in a grant review capacity is grounds for removal from the Board, advisory body, or volunteer role.

ARTICLE VI — VIOLATIONS

SECTION 6.1 — FAILURE TO DISCLOSE

If the governing board or committee has reasonable cause to believe that a Covered Person has failed to disclose actual or possible conflicts of interest, it shall inform the person of the basis for such belief and afford the person an opportunity to explain the alleged failure to disclose.

SECTION 6.2 — CONSEQUENCES

If, after hearing the person's response and after making further investigation as warranted by the circumstances, the governing board or committee determines the person has failed to disclose an actual or possible conflict of interest, it shall take appropriate disciplinary and corrective action, up to and including removal from the Board or MAB.

ARTICLE VII — RECORDS OF PROCEEDINGS

The minutes of the governing board and all committees with board-delegated powers shall contain:

- (a) the names of the persons who disclosed or otherwise were found to have a financial interest, the nature of the financial interest, any action taken to determine whether a conflict of interest was present, and the governing board's decision as to whether a conflict of interest in fact existed; and
- (b) the names of the persons who were present for discussions and votes relating to the transaction or arrangement, the content of the discussion, including any alternatives to the proposed transaction or arrangement, and a record of any votes taken in connection with the proceedings.

ARTICLE VIII — COMPENSATION

SECTION 8.1 — COMPENSATION COMMITTEE

A voting member of the governing board who receives compensation, directly or indirectly, from The Order for services is precluded from voting on matters pertaining to that person's compensation.

SECTION 8.2 — COMPENSATION REVIEW PROCESS

Before The Order pays compensation to any officer, director, or MAB member, the Board shall:

- (a)** appoint a compensation committee of at least two disinterested directors, not including the person whose compensation is being determined;
- (b)** obtain and consider comparability data — compensation paid by similarly situated organizations for similar services; and
- (c)** document the basis for the compensation decision in Board minutes, including the comparability data reviewed.

This requirement applies before any officer of The Order, including the Executive Director and/or Founder, is paid for their service.

SECTION 8.3 — NO COMPENSATION TO MAB FOR ADVISORY SERVICE

Members of the Medical Advisory Board receive no compensation for their advisory service. Travel and accommodation expenses may be reimbursed under the Expense Reimbursement and Accessibility Policy.

ARTICLE IX — ANNUAL STATEMENTS

Each director, principal officer, and member of a committee with governing board-delegated powers shall annually sign a statement affirming that such person:

- (a)** has received a copy of the conflict of interest policy;
- (b)** has read and understands the policy;
- (c)** has agreed to comply with the policy; and
- (d)** understands The Order is charitable and must engage primarily in activities which accomplish one or more of its tax-exempt purposes.

The annual disclosure form is attached as Exhibit A.

ARTICLE X — PERIODIC REVIEWS

To ensure The Order operates in a manner consistent with charitable purposes, periodic reviews shall be conducted covering at a minimum:

- (a) whether compensation arrangements and benefits are reasonable, based on competent survey information, and the result of arm's-length bargaining; and
- (b) whether partnerships, joint ventures, and arrangements with management organizations conform to The Order's written policies, are properly recorded, reflect reasonable investment or payments for goods and services, further charitable purposes, and do not result in inurement, impermissible private benefit, or in an excess benefit transaction.

ARTICLE XI — USE OF OUTSIDE EXPERTS

When conducting the periodic reviews provided for in Article X, The Order may, but need not, use outside advisors. Their use shall not relieve the governing board of its responsibility for ensuring periodic reviews are conducted.

ARTICLE XII — ADOPTION

This Conflict of Interest Policy was adopted by the Board of Directors of The Order of the SWNs Foundation on:

Date: _____

Signed:

Sherry Kinkade, President

Sherry Kinkade, Secretary

**EXHIBIT A — ANNUAL CONFLICT OF INTEREST
DISCLOSURE STATEMENT**

The Order of the SWNs Foundation
Annual Conflict of Interest Disclosure Statement
Year ending December 31, _____

Name:

Role in The Order:

PART 1 — FINANCIAL INTERESTS IN ENTITIES DOING BUSINESS WITH THE ORDER

Do you, or does a member of your immediate family, have an ownership or investment interest, compensation arrangement, or other financial relationship with any entity that has had a transaction with The Order in the past year, or that you expect may have a transaction with The Order in the coming year?

☐ No ☐ Yes — describe (entity name, nature of relationship, approximate value):

PART 2 — PHARMACEUTICAL AND MEDICAL INDUSTRY RELATIONSHIPS

Do you have any current compensated relationship with any pharmaceutical company, medical device company, NF/SWN clinical program, or NF/SWN clinical research sponsor? (Includes speaking fees, consulting fees, research funding, advisory board roles, or equity interests.)

☐ No ☐ Yes — describe (entity name, nature of relationship, approximate annual value):

PART 3 — RELATIONSHIPS WITH ENTITIES SUBJECT TO FORGE AUDIT REVIEW

Do you have any current or recent (within the past three years) compensated relationship with any NF clinic, NF clinical network, or provider organization that might be subject to The Order audit review?

☐ No ☐ Yes — describe:

PART 3B — SWN FUND GRANT ELIGIBILITY

Do you have any current financial relationship with any pharmaceutical company, medical device company, clinical research sponsor, or biotechnology company — including employment, consulting, speaking fees, advisory board roles, or equity interests of any kind?

☐ No ☐ Yes — describe (company name, nature of relationship):

If Yes: you are categorically excluded from all SWN Fund grant review and administration roles under Section 5.4 of this policy, regardless of whether your employer has any connection to any specific grant applicant.

PART 4 — OTHER POTENTIAL CONFLICTS

Are you aware of any other relationship, interest, or circumstance that could create an appearance of conflict between your personal interests and those of The Order?

☐ No ☐ Yes — describe:

CERTIFICATION

I have received, read, and understand The Order's Conflict of Interest Policy. I agree to comply with the policy. I understand that The Order is a charitable organization and that I have an obligation to place the interests of The Order ahead of my own personal financial interests when acting in my capacity as a director, officer, or committee member.

Signature

Date

THREE-YEAR FINANCIAL PROJECTIONS
The Order of the SWNs Foundation

Drafted: 2026-09-06 | For use in: IRS Form 1023, NORD fiscal
sponsorship application, grant applications

EIN: 42-4978003 | **Incorporated:** September 17, 2026 | **State:** Washington
These projections represent The Order’s good-faith estimates based on
comparable rare disease advocacy organizations at similar stages of
development. Year 1 projections reflect pre-501(c)(3) operations under NORD
fiscal sponsorship. All figures are in U.S. dollars.

SUMMARY TABLE

	Year 1	Year 2	Year 3
Total Revenue	\$12,000	\$58,000	\$140,000
Total Expenses	\$9,500	\$54,000	\$128,000
Net (surplus / deficit)	\$2,500	\$4,000	\$12,000
Cumulative reserve	\$2,500	\$6,500	\$18,500

REVENUE DETAIL

Individual Contributions

Revenue Source	Year 1	Year 2	Year 3
Individual donations (small, under \$500)	\$3,000	\$8,000	\$18,000
Major gifts (\$500–\$5,000)	\$2,000	\$10,000	\$25,000
Planned gifts / bequests	\$0	\$0	\$5,000
Individual subtotal	\$5,000	\$18,000	\$48,000

Year 1 individual giving assumes approximately 30–50 donors at an average gift of \$100–\$200, primarily from the SWN patient community and personal network. Year 2 reflects growth as The Order’s public presence expands. Year 3 includes the first bequest or planned gift, which is common for rare disease foundations as donors age into estate planning.

Institutional Grants

Revenue Source	Year 1	Year 2	Year 3
Community foundation / capacity-building grants	\$2,000	\$15,000	\$30,000
Rare disease advocacy grants (NORD, CTF-adjacent)	\$0	\$8,000	\$20,000
Federal grants (DoD CDMRP, NIH R03)	\$0	\$0	\$25,000
Patient advocacy foundation grants (PCORI, PAF)	\$0	\$5,000	\$10,000

Revenue Source	Year 1	Year 2	Year 3
Institutional subtotal	\$2,000	\$28,000	\$85,000

Year 1 institutional grants are limited to small community foundation awards (typically \$1,000–\$5,000 for emerging nonprofits) that do not require established 501(c)(3) status when NORD fiscal sponsorship is in place. Year 2 reflects access to NORD-eligible grants and mid-size rare disease program grants. Year 3 includes first federal grant revenue, anticipated from DoD NF Research Program consumer reviewer pathway or NIH R03 small research grant with an academic partner.

Corporate and Other

Revenue Source	Year 1	Year 2	Year 3
Corporate / pharmaceutical sponsorships	\$0	\$5,000	\$5,000
Event revenue (net of costs)	\$1,000	\$4,000	\$7,000
Game and digital program revenue	\$4,000	\$3,000	\$0
Corporate and other subtotal	\$5,000	\$12,000	\$12,000

Pharmaceutical sponsorships, if accepted, are subject to the Gift Acceptance Policy's audit integrity provisions — no gift is accepted from an entity under active FORGE review, and no gift may be conditioned on audit outcomes. Corporate giving is conservatively projected given The Order's early stage. Game revenue reflects the Flight of the SWN platform's potential for in-game purchases or subscriptions; this is speculative and projected to stabilize as a smaller ongoing contributor.

EXPENSE DETAIL

Program Services

Expense	Year 1	Year 2	Year 3
FIND the SWNs			
Public awareness campaigns (digital, print)	\$500	\$3,000	\$8,000
Clinician education materials	\$300	\$2,000	\$5,000
Game / digital tool maintenance	\$500	\$1,500	\$3,000
Conference presence (NF Society, NORD)	\$1,000	\$3,000	\$5,000
FIND the SWNs subtotal	\$2,300	\$9,500	\$21,000

FUEL with Coin			
Fundraising platform fees	\$200	\$500	\$1,000
Grant writing (time or consultant)	\$0	\$2,000	\$3,000
Donor acknowledgment and stewardship	\$100	\$500	\$1,000
FUEL subtotal	\$300	\$3,000	\$5,000

FLOCK & Raise a Squawk			
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Expense	Year 1	Year 2	Year 3
Community platform (Discord, website)	\$200	\$500	\$1,000
Community events (virtual)	\$0	\$1,000	\$3,000
Community events (in-person)	\$0	\$1,000	\$5,000
Patient travel and accessibility support (SWN Fund)	\$0	\$5,000	\$15,000
FLOCK subtotal	\$200	\$7,500	\$24,000

FORGE the Standards			
Audit methodology development	\$500	\$2,000	\$5,000
Data access and analysis tools	\$200	\$1,000	\$3,000
MAB stipends / travel for audit review	\$500	\$2,000	\$5,000
Publication and dissemination	\$0	\$1,000	\$3,000
FORGE subtotal	\$1,200	\$6,000	\$16,000

Total Program Services	\$4,000	\$26,000	\$66,000
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Management and General

Expense	Year 1	Year 2	Year 3
Legal (nonprofit counsel, annual review)	\$1,500	\$2,000	\$2,500
Accounting / bookkeeping	\$500	\$2,000	\$3,000
IRS Form 1023 filing fee	\$600	\$0	\$0
Washington state filings and annual renewal	\$100	\$100	\$100
Insurance (D&O, general liability)	\$500	\$1,500	\$2,000
Technology (email, cloud storage, website hosting)	\$500	\$1,000	\$1,500
Office and administrative supplies	\$200	\$400	\$500
Bank fees	\$100	\$200	\$200
Management and General subtotal	\$4,000	\$7,200	\$9,800

Payroll and Human Resources

Expense	Year 1	Year 2	Year 3
Executive Director / Founder compensation	\$0	\$0	\$20,000
Mission Coordinator (part-time Year 2, full-time Year 3)	\$0	\$18,000	\$28,000

Expense	Year 1	Year 2	Year 3
Payroll taxes and benefits (est. 15% of salary)	\$0	\$2,700	\$7,200
Payroll processing (Gusto or equivalent)	\$0	\$500	\$600
Workers compensation insurance (WA)	\$0	\$300	\$400
Payroll subtotal	\$0	\$21,500	\$56,200

Year 1 assumes all work is performed by the founder and volunteers. Year 2 assumes hiring a part-time Mission Coordinator (\$18,000 = approximately 20 hrs/week at \$18/hr). Year 3 assumes a full-time Mission Coordinator and first partial-year compensation for the Executive Director/Founder, triggered by revenue sustainability. Executive Director compensation in Year 3 must be approved by the Compensation Committee under the Conflict of Interest Policy before any payment is made.

NORD Fiscal Sponsorship Fee

Expense	Year 1	Year 2	Year 3
NORD fiscal sponsorship administrative fee (est. 8%)	\$960	\$800	\$0

NORD fiscal sponsorship fee is estimated at 8% of funds received through NORD. Year 2 fee is lower because some revenue is received directly by The Order under its own 501(c)(3) after determination. Fee drops to zero in Year 3 when The Order is fully independent.

Total Expense Summary

Category	Year 1	Year 2	Year 3
Program Services	\$4,000	\$26,000	\$66,000
Management and General	\$4,000	\$7,200	\$9,800
Payroll	\$0	\$21,500	\$56,200
NORD fiscal sponsorship fee	\$960	\$800	\$0
Contingency (5% of program expenses)	\$540	\$1,300	\$3,300
Total	\$9,500	\$56,800	\$135,300

The Summary Table at the top shows Year 2 expenses as \$54,000 and Year 3 as \$128,000 — those are the midpoint estimates. This detailed table shows the higher end of the range including contingency. All projections carry a $\pm 20\%$ range depending on grant success and fundraising outcomes.

PROGRAM EXPENSE ALLOCATION

For IRS Form 990 reporting purposes, The Order will track expenses in the following functional categories. Fundraising includes all FUEL with Coin program costs plus the NORD fiscal sponsorship fee.

Category	Year 1	Year 2	Year 3
Program Services	\$4,000 (42%)	\$26,000 (46%)	\$66,000 (49%)
Management and General	\$4,000 (42%)	\$7,200 (13%)	\$9,800 (7%)
Fundraising (FUEL + NORD fee)	\$1,260 (13%)	\$3,800 (7%)	\$5,000 (4%)
Payroll	\$0 (0%)	\$21,500 (38%)	\$56,200 (42%)
Contingency	\$540 (6%)	\$1,300 (2%)	\$3,300 (2%)
Total	\$9,800	\$59,800	\$140,300

Year 1 management/general ratio is high relative to program expenses because The Order is spending on legal, filing, and infrastructure setup that is front-loaded. By Year 3, program services represent approximately half of total expenses, consistent with Charity Navigator's standards and NORD's expectations.

KEY ASSUMPTIONS

Revenue Assumptions

- The Order receives NORD fiscal sponsorship approval in Year 1 (required for many grants and for tax-deductible donations before IRS determination)
- IRS 501(c)(3) determination is received by the end of Year 1 or early Year 2
- Individual fundraising grows from the existing SWN patient community network

- At least one community foundation capacity-building grant of \$1,000–\$3,000 is awarded in Year 1 without 501(c)(3) status (possible under NORD sponsorship)
- No pharmaceutical corporate gifts are budgeted in Year 1 pending FORGE audit integrity protocols being fully in place

Expense Assumptions

- Legal and accounting costs are for an attorney who works with small nonprofits (estimated \$250–\$350/hour for formation and annual review)
- Conference attendance costs assume 1–2 attendees at NF Society annual meeting and NORD conference
- No full-time payroll until Year 2 at the earliest
- All Year 1 program work is performed by the founder and volunteer community

Sensitivity

- If NORD fiscal sponsorship is delayed beyond 6 months, Year 1 revenue drops to approximately \$5,000–\$7,000 (individual network only)
- If a \$15,000–\$25,000 capacity-building grant is secured in Year 2, The Order may hire a Mission Coordinator earlier than projected

- Federal grant revenue in Year 3 is speculative; if not received, Year 3 total revenue is approximately \$95,000–\$115,000

IRS FORM 1023 — PART IX FORMAT

This is the simplified table that goes directly into Form 1023 Part IX. The IRS asks for the current year plus 2 projected years. The Order was incorporated September 17, 2026; the current tax year (2026) is a partial year with no financial activity yet. Year 1 = 2027, Year 2 = 2028.

Revenue

Line	Source	2026 (partial)	2027	2028
1	Gifts, grants, and contributions	\$0	\$7,000	\$46,000
2	Membership fees	\$0	\$0	\$0
3	Gross receipts from exempt-purpose activities	\$0	\$5,000	\$12,000
4	Gross receipts from non-exempt activities	\$0	\$0	\$0
5	Other income	\$0	\$0	\$0
	Total Revenue	\$0	\$12,000	\$58,000

Expenses

Line	Category	2026 (partial)	2027	2028
1	Expenses for exempt purpose (programs)	\$0	\$4,000	\$26,000
2	Compensation of officers/directors/trustees	\$0	\$0	\$0
3	Other salaries and wages	\$0	\$0	\$18,000
4	Interest	\$0	\$0	\$0
5	Occupancy (rent, utilities)	\$0	\$0	\$0
6	Depreciation	\$0	\$0	\$0
7	Other expenses (legal, filing, insurance, tech, NORD fee)	\$700	\$5,500	\$10,000
	Total Expenses	\$700	\$9,500	\$54,000
	Net surplus / (deficit)	(\$700)	\$2,500	\$4,000

2026 expenses represent the IRS Form 1023 filing fee (\$600) and WA Initial Report fee (~\$100). No revenue has been received; the bank account has not been opened.

Net Assets

	2026	2027	2028
Net assets at beginning of year	\$0	(\$700)	\$1,800

	2026	2027	2028
Surplus / (deficit)	(\$700)	\$2,500	\$4,000
Net assets at end of year	(\$700)	\$1,800	\$5,800

The 2026 deficit reflects pre-revenue formation expenses (filing fees) paid by the Founder before the bank account is open. These will be reimbursed to the Founder under the Expense Reimbursement Policy once the bank account is established.

NOTES FOR IRS FORM 1023

These projections are submitted with Form 1023 as required. The IRS asks for projections for the current year and the next two years if The Order has not yet completed its first year, or for the two years after the application year if The Order is established. All projections are The Order's good-faith estimates; actual results will vary. The Order commits to:

- Filing Form 990-N annually until gross receipts exceed \$50,000
- Filing Form 990-EZ when gross receipts are between \$50,000 and \$200,000
- Filing Form 990 when gross receipts exceed \$200,000
- Making annual 990 filings publicly available on The Order's website

CODE OF CONDUCT

The Order of the SWNs Foundation

This Code of Conduct applies to all directors, officers, members of the Medical Advisory Board (The Consular Circle), members of the Patient Advisory Council (The Pathfinders), members of the Volunteer Council (The Bevy of SWNs), Industry Partners and their representatives, volunteers, staff, contractors, and participants in any of The Order's programs, events, platforms, or community spaces.

ARTICLE I — PURPOSE

The Order of the SWNs Foundation exists because schwannomatosis patients have spent too long being dismissed, misdiagnosed, and left without community. We are building something different: a place where patients are at the center, where science is taken seriously, where accountability is not a threat but a tool, and where every person who walks through our door — as a volunteer, a board member, a patient, a clinician, or a curious newcomer — is treated with dignity.

This Code of Conduct is the standard we hold ourselves to. It is not a list of rules designed to manage liability. It is a statement of who we are and how we treat each other — because the community we build inside The Order is the same community we are fighting for outside of it.

Everyone associated with The Order — in any capacity — is expected to read, understand, and uphold this Code.

ARTICLE II — WHO IS COVERED

This Code applies to:

- All members of the Board of Directors and officers
- All members of the Medical Advisory Board (The Consular Circle)
- All members of the Patient Advisory Council (The Pathfinders)
- All members of the Volunteer Council (The Bevy of SWNs)
- All Industry Partners and their representatives while acting in connection with The Order
- All employees and contractors
- All participants in The Order's events, programs, and community spaces — including online platforms, Discord servers, social media groups, forums, and any other space The Order operates or moderates
- All guests, speakers, and partners engaging with The Order in any capacity

If you are doing something under The Order's name or in any space operated by The Order, this Code applies to you.

ARTICLE III — CORE COMMITMENTS

Everything in this Code flows from five commitments. When in doubt about how to act, come back to these.

1. We treat every person with dignity.

Every person who encounters The Order — patient, clinician, researcher, volunteer, skeptic — is treated as a person first. Chronic illness does not diminish dignity. Disagreement does not forfeit it. We do not demean, belittle, or dismiss.

2. We tell the truth.

We represent The Order's work accurately. We do not exaggerate findings, overstate credentials, misrepresent the science, or say things we know to be false. When we don't know something, we say so. When we are wrong, we correct the record.

3. We protect the vulnerable.

Schwannomatosis patients are medically vulnerable. Many are in pain. Many have histories of trauma with the healthcare system. We handle patient information, patient stories, and patient trust as the precious things they are. We do not exploit patient experiences for organizational gain.

4. We keep the mission clean.

The Order's credibility — especially the credibility of FORGE the Standards — depends on staying grounded in evidence and free from personal agendas. We do not use The Order's platforms to pursue personal grievances. We do not mix our own experiences with The Order's published findings. Personal stories are valid and valued; they are not audit data.

5. We hold ourselves accountable.

We follow the rules we set for others. We report violations we witness. We accept correction with grace. We do not protect people who violate this Code because they are well-liked or well-credentialed.

ARTICLE IV — RESPECTFUL CONDUCT

Section 4.1 — Anti-Harassment

Harassment of any kind is prohibited in all The Order's spaces and activities. Harassment includes:

- Verbal or written abuse, threats, or intimidation
- Unwelcome sexual attention, comments, or contact
- Deliberate humiliation, public shaming, or targeted mockery
- Repeated unwanted contact after being asked to stop
- Any conduct that a reasonable person would find hostile, demeaning, or threatening

Harassment applies equally in person, by email, in Discord, in social media comments, in video calls, and in any other medium associated with The Order.

Section 4.2 — Anti-Discrimination

The Order does not tolerate discrimination based on race, color, national origin, ethnicity, religion, sex, gender identity or expression, sexual orientation, age, disability, medical condition, genetic information, marital status, caregiver status, socioeconomic background, or any other characteristic protected by applicable law.

The Order was built by and for a patient community that knows what it is to be dismissed because of how you present. We do not replicate that here.

Section 4.3 — Accessibility and Accommodation

The Order is committed to making its programs and spaces accessible to participants with disabilities, chronic illness, pain conditions, cognitive differences, and any other access need. Participants who need an accommodation should contact The Order at foundation@theorderoftheswns.org. We will work to meet every reasonable request.

Schwannomatosis patients in particular may experience variable capacity — pain flares, surgical recovery, fatigue, cognitive effects of treatment. The Order designs its programs with variable capacity in mind and does not penalize members for health-related unavailability when communicated in good faith.

Section 4.4 — Conflict Resolution

Interpersonal conflicts happen. When they do:

- Address the issue directly and respectfully with the other person when possible and safe
- If direct resolution is not possible or appropriate, bring the concern to:
 - The Bevy Council Chair (for conduct in volunteer and community spaces)
 - The MAB Chair or Executive Director (for conduct involving MAB members or The Consular Circle)
 - The Executive Director (for conduct involving staff, contractors, or Pathfinder members)
 - The Board Chair (for governance matters, officer conduct, or Industry Partner conduct)
- Do not escalate publicly — airing conflicts in community spaces, social media, or public channels is harmful to The Order and to the people involved

ARTICLE V — PATIENT COMMUNITY CONDUCT

This section applies specifically to The Order’s community spaces — including Discord, online forums, social media groups, events, and any other platform where patients, families, and the public gather under The Order’s name.

Section 5.1 — Space for Anger and Grief

Living with schwannomatosis is hard. Many in our community carry years of misdiagnosis, medical dismissal, financial devastation, and loss. Anger about that is legitimate. Grief about that is legitimate. The Order’s community spaces are not required to be relentlessly positive, and participants are not required to perform gratitude or resilience they don’t feel.

What is required is that anger and grief be directed at systems, patterns, and circumstances — not at specific individuals in personal attacks, and not at each other.

Section 5.2 — Medical Information and Advice

Community members may share their own experiences with diagnosis, treatment, medication, and clinical care freely. Community members may not present personal experience as medical advice applicable to others, diagnose other community members, recommend specific treatments as appropriate for someone else’s case, or discourage others from pursuing medical evaluation or treatment.

The Order’s community spaces are a source of connection and shared experience — not a substitute for clinical care. We will remind community members of this often and without judgment.

Section 5.3 — Discussing Providers and Clinics

Community members may share their own personal experiences with specific providers and clinics — including negative experiences. Lived experience is valid and The Order does not silence it.

What is not permitted is coordinated targeting, pile-ons, or campaigns against specific individuals or institutions in The Order’s spaces. There is a difference between “here is what happened to me at [clinic]” and organizing a community response against a named individual. The former is protected. The latter is not a function of The Order and will be redirected.

Formal findings about providers and clinics come from the FORGE the Standards audit process — not from community discussion. The Order keeps this separate to protect both the community and the integrity of the audit.

Section 5.4 — Privacy of Other Community Members

What is shared in The Order’s community spaces is shared in confidence. Community members do not screenshot, share, or republish other members’ personal disclosures — including health information, family circumstances, financial situations, or experiences with providers — outside the space where they were shared, without that person’s explicit consent.

Patient stories are The Order’s most sacred asset. We protect them accordingly.

Section 5.5 — Welcoming New Members

Every person who joins The Order’s community arrives carrying a history we may not know. Some have just received a diagnosis. Some have been searching for years. Some have lost something — a surgery that changed their body, a treatment that didn’t work, a doctor who dismissed them. The standard for how we welcome new members is the welcome we wish we had received when we were new.

ARTICLE VI — SCIENTIFIC AND CLINICAL INTEGRITY

This section applies to all The Order’s participants who engage in The Order’s scientific, clinical, or audit-related work, including FORGE the Standards activities, Medical Advisory Board functions, published materials, and public statements about clinical care.

Section 6.1 — Evidence Basis

All The Order’s findings, reports, position statements, and public claims about clinical care must be grounded in the published medical literature, verified data, or The Order’s documented audit methodology. Anecdote, personal experience, and community reports are valuable inputs — they are not audit findings.

Participants must not represent personal experience, community reports, or unverified information as The Order’s findings.

Section 6.2 — Separation of Personal Grievance and Audit Work

The Order's participants who have personal experiences with NF clinics, providers, or institutions — including negative experiences — may share those experiences in community spaces under Section 5.3. Those experiences must not be mixed into The Order's audit process, represented as audit findings, or used to drive audit priorities in a way that substitutes personal grievance for evidence-based methodology.

The audit process is the audit process. Personal experience is personal experience. Both matter. They are not the same thing.

Section 6.3 — Intellectual Honesty

Participants engaged in The Order's scientific and clinical work are expected to:

- Represent findings accurately and completely, including findings that do not support the conclusion they expected or hoped for
- Acknowledge uncertainty when it exists
- Update positions when new evidence warrants it
- Attribute sources accurately and completely
- Never misrepresent a cited study's findings

Section 6.4 — No Retaliation Through The Order's Channels

The Order's programs — including its audit framework, community platforms, and public materials — may not be used to retaliate against any person, provider, or institution for personal reasons unrelated to The Order's exempt mission. Participants who attempt to use The Order's channels for personal retaliation will have their access revoked.

ARTICLE VII — CONFIDENTIALITY AND PRIVACY

Section 7.1 — The Order’s Confidential Information

Participants who have access to non-public information of The Order — including financial records, personnel matters, donor information, audit materials, pre-publication findings, Board deliberations, and patient data — agree to treat that information as confidential. Confidential information may not be shared outside the person’s authorized role without written permission from the Board Chair or Executive Director.

This obligation survives a person’s departure from any role with The Order.

Section 7.2 — Patient Information

Patient information is handled with the highest standard of care. Any participant who has access to individually identifiable patient information in connection with The Order’s programs agrees to:

- Use that information only for the authorized program purpose
- Not share it with any unauthorized person
- Not retain it beyond the period necessary for the program purpose
- Report any suspected breach immediately to the Executive Director

Section 7.3 — No Unauthorized Recording

Participants in The Order’s meetings, events, and community spaces may not record audio or video of other participants without the explicit consent of all participants being recorded. This applies to Board meetings, MAB meetings, Bevy meetings, community events, and any other gathering of The Order.

ARTICLE VIII — USE OF THE ORDER’S NAME AND RESOURCES

Section 8.1 — Authorized Use Only

The Order’s name, logo, brand assets, and organizational identity may be used only in ways authorized by the Board of Directors or Executive Director. No participant may:

- Represent themselves as speaking officially for The Order without authorization
- Use The Order’s name in connection with their personal business, advocacy, or political activity without Board approval
- Create materials that appear to be official communications of The Order without approval

Section 8.2 — The Order’s Resources

The Order’s resources — including equipment, software, financial accounts, donor data, and email systems — are for The Order’s purposes only. Personal use of The Order’s resources is not permitted without explicit approval.

Section 8.3 — Intellectual Property

Materials created in the course of The Order’s work — including research, writing, designs, tools, and other deliverables — belong to The Order unless a written agreement specifies otherwise. Participants may not repurpose or republish The Order’s work product under their own name or for their own benefit without written permission.

ARTICLE IX — PUBLIC COMMUNICATIONS AND SOCIAL MEDIA

Section 9.1 — Personal vs. Official Voice

Participants may have their own personal social media presence and may hold their own opinions on matters unrelated to The Order. When posting personally about The Order, participants should make clear that they are sharing their own perspective, not an official position of The Order.

Participants may share The Order’s public materials, publications, and announcements freely and are encouraged to do so.

Section 9.2 — What Not to Post

In personal or professional social media and public communications, The Order’s participants agree not to:

- Disclose confidential information of The Order
- Share pre-publication audit findings or draft materials

- Make statements about specific providers or clinics that go beyond what The Order has formally published
- Represent The Order's position on matters where no official position has been adopted
- Post content that a reasonable person would find harassing, defamatory, or harmful to identified individuals

Section 9.3 — Media Inquiries

If a participant receives a media inquiry related to The Order, they should notify the Board Chair or Executive Director before responding. The Order's designated spokesperson handles media inquiries unless the Board designates otherwise.

ARTICLE X — REPORTING VIOLATIONS

Section 10.1 — How to Report

Any person who witnesses or experiences a violation of this Code may report it to:

- **The Bevy Council Chair** — for conduct in volunteer and community spaces
- **The MAB Chair** — for conduct involving members of the Medical Advisory Board (The Consular Circle)
- **The Executive Director** — for conduct involving staff, contractors, Pathfinder members, or program activities
- **The Board Chair** — for conduct involving the Executive Director, Board members, or Industry Partners
- **foundation@theorderoftheswns.org** — for any concern, including anonymous reports

Reports may be made in writing, by email, or verbally. Anonymous reports are accepted.

Section 10.2 — Good Faith Reports Are Protected

Anyone who reports a Code of Conduct violation in good faith is protected from retaliation. Retaliation against a reporter is itself a serious Code violation and will be treated accordingly. See also The Order's Whistleblower Policy.

Section 10.3 — False Reports

Reports made in bad faith — designed to harm a person rather than address a genuine violation — are themselves a violation of this Code.

Section 10.4 — Response Process

Upon receiving a report, The Order will:

- Acknowledge receipt within **five (5) business days** (to the extent the reporter is identifiable)
- Assess whether the report describes a Code violation and what response is appropriate
- Take interim protective measures if needed to protect the reporter or others while the matter is reviewed
- Conduct a review proportionate to the seriousness of the reported conduct
- Communicate the outcome to the reporter to the extent permitted by confidentiality

ARTICLE XI — CONSEQUENCES

Consequences for Code violations are proportionate to the conduct and may include:

For first or minor violations:

- Private conversation and coaching
- A written warning
- Temporary restriction from specific spaces within The Order or activities

For serious or repeated violations:

- Removal from a specific role, working group, or community space
- Suspension from all The Order's activities for a defined period
- Permanent removal from membership in The Order, volunteer status, or any role with The Order

For directors and officers:

Serious Code violations may be grounds for removal from the Board in accordance with The Order's Bylaws.

For MAB members:

Serious Code violations may be grounds for removal from the Medical Advisory Board in accordance with the MAB Charter.

For Pathfinder members:

Serious Code violations may be grounds for removal from the Patient Advisory Council in accordance with the Pathfinders Charter.

For Industry Partners:

Serious Code violations may result in suspension or termination of the Industry Partnership Agreement, as determined by the Board of Directors.

The Order will apply consequences consistently and without favoritism. Seniority, credentials, patient status, or relationship with The Order's leadership do not exempt anyone from accountability under this Code.

ARTICLE XII — ADOPTION AND ACKNOWLEDGMENT

Section 12.1 — Adoption

This Code of Conduct was adopted by the Board of Directors of The Order of the SWNs Foundation on:

Date:

Signed:

Sherry Kinkade, President

Sherry Kinkade, Secretary

Section 12.2 — Annual Acknowledgment

All covered persons shall receive a copy of this Code annually and sign the acknowledgment below confirming they have read and agree to uphold it.

EXHIBIT E-1 — CODE OF CONDUCT ACKNOWLEDGMENT

THE ORDER OF THE SWNS FOUNDATION

Code of Conduct — Annual Acknowledgment

I have read the Code of Conduct of The Order of the SWNs Foundation. I understand what it requires of me and I commit to upholding it in all my activities associated with The Order — in person, online, and in any other context where I represent The Order or act under its name.

I understand that violations of this Code may result in consequences up to and including removal from my role with The Order.

Name (print):

Role / Capacity:

(Director / Officer / MAB Member — The Consular Circle / Pathfinder — Patient Advisory Council / Bevy Member — Volunteer Council / Industry Partner / Staff / Contractor / Other)

Signature:

Date:

Return to: foundation@theorderoftheswns.org