FORMING A NONPROFIT: WHERE TO INCORPORATE AND FILING THE ARTICLES OF INCORPORATION

Presented By: Kayla Pfab, President
Transplant Unwrapped
WHY SHOULD YOU INCORPORATE YOUR NONPROFIT?

• It registers and secures your organization’s name in your state of incorporation.

• It limits the personal liability of your directors and/or members.

• It adds credibility to your organization.

• It paves the way to applying for 501(c)(3) federal tax exemption status.
WHERE SHOULD YOU INCORPORATE?

“Resident State” or State of Non-Profit Operations, where the majority of your:

- Board members reside.
- Funds are raised.
- Events or activities are held.
WHERE SHOULD YOU INCORPORATE?

What about Delaware?

• Beneficial to **for-profit** businesses to incorporate in Delaware.

• No benefit to nonprofits seeking 501(c)(3) tax exempt status.

• If Delaware is not your resident state, you will pay more fees in the long run to incorporate there.

Not Tied to One Particular State?

• Review state regulations, charitable solicitation policies and filing fees for nonprofit organizations in which each board member resides.

• Based on findings, select the state with the lowest fees and most straightforward regulations.
FILING YOUR ARTICLES OF INCORPORATION

Determine Your State’s Requirements for Filing Nonprofit Articles of Incorporation

• Usually through the Secretary of the State.
• The Secretary of the State’s Office website usually has a Certificate of Formation form to fill out with required information for incorporation.
• Many websites available that offer “guides” for state-by-state requirements.


Candid State-by-State Guide: https://learning.candid.org/resources/nonprofit-startup-resources/
Choosing a Name for Your Nonprofit

- Business entity (name) search on the Secretary of the State’s website.
- Verify your name is available as a domain name on the internet.
- Ensure your name describes your organization’s mission.
- Keep it simple and memorable.
Registered Agent and Registered Office
- Receives legal and tax documents.
- Must have physical address (No P.O. box).

Director(s)
- Names and addresses of initial directors/board members.
- Minimum number requirements vary per state.

Membership
- Indicate whether your nonprofit will or will not have members.

Purpose
- Purpose of the organization.
- Important to include additional language indicating the charitable purposes of your organization for when you submit the articles of incorporation with your 1023 501(c)(3) tax-exempt application (see next slide).

Incorporator(s) or Organizer(s)
- Individual(s) responsible for executing the articles of incorporation.
- Registered agent and incorporator/organizer can be the same person.
The following text may be used to define your purpose which is needed to obtain tax-exempt status:

[Transplant Unwrapped, Inc.] is organized for exclusively religious, 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 United States Internal Revenue Law, including, for such purposes, the making of distributions to organizations that qualify as exempt organizations under said Section 501(c)(3) of the Internal Revenue Code of 1986.

- Notwithstanding any other provision of these Articles, this organization shall not carry on any activities not permitted to be carried on by an organization exempt from Federal Income Tax under Section 501(c)(3) of the Internal Revenue Code of 1986 or the corresponding provision of any future United States Internal Revenue Law or by an organization, contributions to which are deductible under Section 170(c)(2) of the Internal Revenue Code, or corresponding section of any future federal tax code.

- No substantial part of the activities of the corporation shall be carrying on propaganda, or otherwise attempting to influence legislation, and the organization shall not participate in, or intervene in (including the publication or distribution of statements), any political campaign on behalf of any candidate for public office.
• No part of the net earnings of the corporation shall inure to the benefit of, or be distributable to its members, trustees, officers, or other private persons, except that the organization shall be authorized and empowered to pay reasonable compensation for services rendered and to make payments and distributions in furtherance of the purposes set forth in the purpose clause hereof.

Dissolution Text

• Upon the dissolution of the corporation, the Board of Directors shall, after paying or making provision for payment of all the liabilities of the corporation, dispose of the residual assets of the corporation exclusively for exempt purposes of the corporation in such manner, or to one or more organizations which themselves are exempt as organizations described in Sections 501(c)(3) and 170(c)(2) of the Internal Revenue Code of 1986 or corresponding Sections of any future Internal Revenue Code. 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 corporation is then located, for such purposes or organizations, as said Court shall determine, which are organized and operated exclusively for such purposes.
FILING YOUR ARTICLES OF INCORPORATION

Submitting Articles of Incorporation
- Mail in or submit online, varies by state.
- Pay filing fees, varies by state ~$25-$100.
- Turnaround time varies by state, ~1-4 weeks; some states can expedite for an increased fee.

Additional Step in Some States
- Publish notice of your intention to file, or of your filing of the Articles of Incorporation.
- Typically, specific language is required and there are guidelines about which legal publications or newspapers should be used.
- Example: If filing in Pennsylvania, publication of either the intent to file or the actual filing of Articles of Incorporation must be made in two newspapers of general circulation, one a legal journal, if possible. Find more information on the PA Department of State’s website.
THANK YOU

Kayla Pfab
President, Transplant Unwrapped
Email: kayla@transplantunwrapped.org
THE “BUSINESS” OF TREATMENT

Bina Shah, Founder & CEO
Project 8p Foundation
FIRST 8p CONFERENCE, 6 MONTHS AFTER FORMATION

from strangers to family
PROJECT 8p ACHIEVEMENTS IN 2 YEARS

2018
- Nov, Formed Project 8p Foundation
- Shah family funds Research. Registry launched goal 100 participants

2019
- June, First Conference NYC
- 100+ Volunteers signed up
- 200 registry participants
- Website Launch

2020
- Sept, 1st Scientific Advisory Board Meeting
- Org capacity growing Patient Leadership Board
- Hired Research Director
- Aug, Sponsored research in advanced genomics
- 2nd Virtual Conference
- Biobank Contract Executed
- Nov, IRB Approval
- 200 registry participants

2021
- Mar, Commission on Novel Technologies for Neurodevelopmental Copy Number Variants - Hosted Virtual Conference
- Aug, 2nd Virtual Conference
- 1st Clinic Setup
- Private research community 764 members
- June, Published Trend Community Voice Report
- Network For Good Donor Mgmt software
- Donorbox Donor Mgmt software
VISION, MISSION, GOALS

• FIRST: What is your Why?
• SECOND: What problem are you trying to solve? (the end in sight)

**Future State**

2025 press release

First Chromosome Therapy significantly improves motor function, cognition, speech, and increases longevity.

Patients led the path to treatment by uniting stakeholders.

In 2018, 8p disorders were poorly understood with no active researchers and no expert clinicians.

Today in 2025, this 8p hero can express that, “We have no fight. Fight implies obstacles. Our fight is not what gave us a meaningful life. Perseverance and collaboration did.”

**Strategic Planning:**

- **Vision** – preferred state of future and direction
- **Mission** - helps us focus on who we are, what we do, and why
- **Goals** - broad, long-term aims that define the fulfillment of our mission
- **Objectives** - specific, quantifiable, relevant targets that measure the accomplishment of a goal

Landscape Assessment or your SWOT Analysis

Benchmarking Interview Guide - operating budgets, strength of team, what they have achieved, what can you do better.

**Orgs are willing to pay it forward. Learn from everyone’s mistakes.**
WHY SHOULD ANYONE CARE?

There is no cure or treatment

Rare diseases impact more people than cancer and AIDS combined

US 30 MM people
Globally 400 MM people
• 1/10 people in the US affected
• 1/17 people globally in their lifetime will have a rare disease

Genome sequencing makes what wasn't possible ten years ago possible now.

Can scientists crack the code for many brain diseases with our genomic data?

50% affected are children
• Invest in People – Passionate and Proactive people who work well together
• Whomever you identify and recruit, your role as a leader is to keep everyone engaged closely connected to those affected and the mission.
• Don’t start with titles. Think about the activities and responsibilities you want people to manage (or complete).
• Then you develop roles.
• Everyone is an owner. The most successful companies, from start-ups to public conglomerates, are the ones where employees have a stake/stock.

You cannot bring in the Patient’s Voice and have Patient-led endeavors when you choose. It is every step of the way.

• All of your stakeholders –
  • Patients/Families in your community
  • Doctors/Clinicians
  • Researchers
  • Funders
  • Industry
  • Regulators
Thank you!

Contact me at bina@project8p.org

Bina Shah
“JUST RIGHT” BYLAWS FOR YOUR ORGANIZATION

Julie Raskin, MA
Executive Director
Congenital Hyperinsulinism International
We founded CHI in 2005 to support congenital hyperinsulinism (HI) research for better treatments and cures, and to raise awareness of HI to reduce brain damage and death as well as improving access to care and treatment for those with HI and providing a community for HI families.
It was 2005, so we gathered by conference call (before the video chat era). In the early months, we spent a lot of time thinking about our mission, our name and how we would govern our organization. Once we were comfortable with our mission, we set the goal of developing bylaws to guide our actions and decisions.
RESOURCES WE USED TO DEVELOP BYLAWS

- New Mexico Secretary of State (Look for resources in the state or states in which you will incorporate)
- New Jersey Center for Nonprofits
- Bylaws of Boards We Knew About
- Internet Searches
- Books
- BoardSource (I didn’t know about it back then but now consider it a great resource. It comes with a NORD membership!)
- Human Resources—Board Members with legal and nonprofit backgrounds.
SOME WRITING BYLAWS WISDOM FROM BOARDSOURCE “DOs AND DON’Ts”

• Don’t worry about drafting perfect bylaws the first time around. Start with very basic bylaws that cover major issues surrounding meetings and elections, and then slowly amend those bylaws over time.

• Do review the bylaws periodically and ensure timely amendments when necessary.

• Include a clause granting the board the ability to form committees and task forces as the need arises rather than naming all committees and their descriptions in the bylaws.

• When addressing the size of the board, don’t specify an exact number. A range allows for the most flexibility, e.g., "no fewer than five and no more than 15 members."

• Don’t include a full conflict-of-interest policy in the bylaws. Instead, reference a standalone conflict-of-interest policy housed in a separate document that can be quickly amended by the board.
Feel free to reach out: Jraskin@congenitalhi.org
ABCs & 123s OF NONPROFIT FORMATION: WALKING THE PATH WITH OTHERS
FILE FOR AN EMPLOYEE IDENTIFICATION NUMBER AND FILE FOR 501(C)(3) STATUS

Seth Rotberg, MNM
Co-Founder and Board President
Our Odyssey
FILING FOR EMPLOYEE IDENTIFICATION NUMBER (EIN)

Fill out the SS-4 application to obtain your EIN number (www.irs.gov/FormSS4)

Legal name of entity is your organization’s name, not your own

Enter the address you plan on using when filing for 501(c)(3)
  • Use a physical address, not a PO Box

Type of entity → most likely is “other nonprofit organization”
  • Put down charitable organization or research foundation

Fiscal vs. calendar year
FILING FOR 501(C)(3) STATUS

- Fill out the Form 1023 application to obtain your 501(c)(3) status (www.irs.gov/Form1023)
- Get prepared
  - Need your EIN from the IRS, bylaws, articles of incorporation and board of directors
- 1023 vs. 1023-EZ
  - 1023 costs $600
  - 1023-EZ costs $250
    - Projected annual gross receipts must not exceed $50,000 in any of the next 3 years
• Additional costs such as obtaining a domain and website
  › Put together GoFundMe to kickoff your fundraising
• Annual filing
  › 990 for tax purposes
  › In MA, we also need to provide a brief update each year about our nonprofit
• Prepare additional policies such as conflict of interest, confidentiality and social media
Let’s connect if I can help!
Email: seth@ourodysssey.org
Twitter/Instagram: @srotberg15
HOLDING YOUR ORGANIZATION’S INAUGURAL BOARD MEETING

Lisa Manaster, Co-Founder and President
CACNA1A Foundation
ABOUT THE CACNA1A FOUNDATION

• Founded in March 2020 to support CACNA1A-related diseases (epilepsy, ataxias, hemiplegic migraine, ID/autism, cerebellar atrophy)

• **Mission:** To increase awareness of CACNA1A genetic mutations, to support families through education and to raise funds for research and treatment options in order to make a difference in the lives of those affected by CACNA1A variants.

• **Inaugural board meeting** - March 8, 2020
HOW TO HOLD AN EFFECTIVE BOARD MEETING – BEST PRACTICES

• Be organized
  › Know your bylaws (e.g. requirements re: communication of meetings - date, time, place, purpose)
  › Assign roles - In some states, one person cannot serve more than one position
  › Quorem - Attendance important

• Be efficient and productive
  › Limit the length of the meeting
  › Present the agenda ahead of time and stick to it!

• “Tone at the top”
  › Casual or more formal?
  › Create a positive culture within the organization
  › Transparency

• Know the rules of running a meeting
  › When to make a motion/ask someone to second it, etc.
    o Roberts Rule of Order – procedural guide

• Document the meeting
  › Minutes should reflect the discussions/decisions

• Thank your board!
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduce main motion</td>
<td>&quot;I move to...&quot;</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Majority</td>
</tr>
<tr>
<td>Amend a motion</td>
<td>&quot;I move to amend the motion by...&quot; (add or strike words or both)</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Majority</td>
</tr>
<tr>
<td>Move item to committee</td>
<td>&quot;I move that we refer the matter to committee.&quot;</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Majority</td>
</tr>
<tr>
<td>Postpone item</td>
<td>&quot;I move to postpone the matter until...&quot;</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Majority</td>
</tr>
<tr>
<td>End debate</td>
<td>&quot;I move the previous question.&quot;</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Majority</td>
</tr>
<tr>
<td>Object to procedure</td>
<td>&quot;Point of order.&quot;</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Chair decision</td>
</tr>
<tr>
<td>Recess the meeting</td>
<td>&quot;I move that we recess until...&quot;</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Majority</td>
</tr>
<tr>
<td>Adjourn the meeting</td>
<td>&quot;I move to adjourn the meeting.&quot;</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Majority</td>
</tr>
<tr>
<td>Request information</td>
<td>&quot;Point of information.&quot;</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No vote</td>
</tr>
<tr>
<td>Overrule the chair’s ruling</td>
<td>&quot;I move to overrule the chair’s ruling.&quot;</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Majority</td>
</tr>
<tr>
<td>Extend the allotted time</td>
<td>&quot;I move to extend the time by ___ minutes.&quot;</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>2/3</td>
</tr>
<tr>
<td>Enforce the rules or point out incorrect procedure</td>
<td>&quot;Point of order.&quot;</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No vote</td>
</tr>
<tr>
<td>Table a Motion</td>
<td>&quot;I move to table...&quot;</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Majority</td>
</tr>
</tbody>
</table>
To transact initial business & get your activities and operations started:

1) Confirm directors/Appoint officers
2) Report on the filing of the Articles of Incorporation
3) Adopt Bylaws and governance policies
4) Conduct start-up formalities
   a) Decide on legal address (not a PO box)
   b) Dates of fiscal year
   c) Schedule for board meetings/annual meeting
   d) Set up bank accounts/co-signers
   e) Corporate seal
• The agenda - Clear, supported by the necessary documents and circulated prior to the meeting as designated in the bylaws?
• Attendance - Board members present?
• Preparation – All came prepared to discuss the materials sent in advance?
• Opinions - A diversity of opinions expressed/issues were dealt with in a respectful manner?

• Effective - The Board Chair facilitated the meeting effectively? Members participated responsibly and were actively engaged?
• Next steps identified and responsibilities assigned?
• Efficient – Meeting began and ended on time?
• Positive working environment? Team atmosphere?
• Finally, it’s a JOURNEY! Don’t stress because there will be many more meetings in your future!
THANK YOU!

Feel free to reach out anytime:
Lisa Manaster
Lisa@cacna1a.org
STATE LICENSES AND TAX EXEMPTIONS FOR 501(C)(3) ORGANIZATIONS

Michael Raymond
Executive Director
The Snyder-Robinson Foundation
michael.raymond@snyder-robinson.org
STATE TAX & REGULATORY REQUIREMENTS TO CONSIDER

Licensure & Taxation of Business, Generally

• Annual or Biennial Reports
  *(registration is usually with Secretary of State, while registration for tax purposes is usually with Dept. of Revenue or Comptroller’s Office)*
• Income Tax
• Sales and Use Tax
• Payroll and Employment Tax
• Property Tax
• Business License Tax
• Other State Taxes
• Unclaimed Property Reporting
STATE REGULATION & TAXATION OF 501(C)(3) ORGANIZATIONS

• **Annual or Biennial Reports** – Required by every state. Be sure to file.

• **Income Tax** – Generally, only “Unrelated Business Income” is taxable.

• **Sales & Use Tax** – All retailers required to report retail sales and collect tax.

• **Sales & Use Tax Exemptions** – Available in some states if requirements are met.

• **Payroll & Employment Tax Returns** – All employers are required to comply.

• **Property Tax Returns** – Local rules apply; exemptions are available.

• **Business License Tax Returns** – Local rules apply, exemptions are available.

• **Unclaimed Property Reporting** – All property “holders” required to comply.

• **Charitable Solicitation Registration** – For non-profits, also consider requirements for Charitable Solicitation Registration.
SALES AND USE TAX EXEMPTIONS

- Many states provide tax exemptions for purchases made by nonprofits.
- Purchases must be used to carry on the business of the nonprofit.
- Exemption certificates are typically required.
- State registration may be required.
- Sales made by nonprofits are generally subject to tax.
- Confirm the rules in your state.
Thank you.