



NORD®
National Organization
for Rare Disorders

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

Presented By: Kayla Pfab, President
Transplant Unwrapped

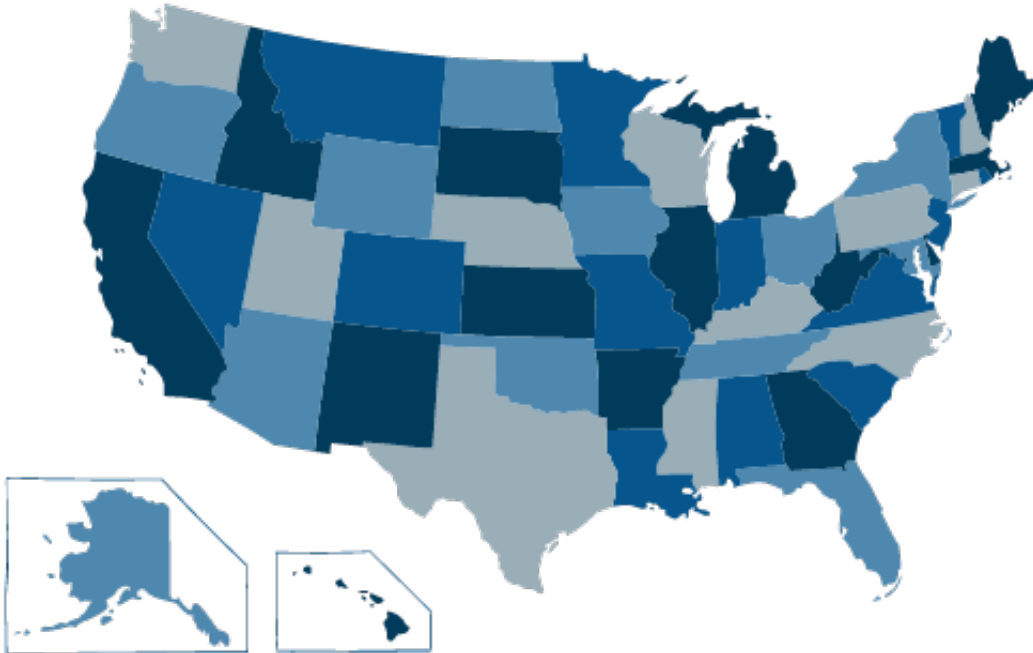


WHY SHOULD YOU INCORPORATE YOUR NONPROFIT?

- 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.

Harbor Compliance State-by-State Guide:

<https://www.harborcompliance.com/information/nonprofit-governance-by-state>

Candid State-by-State Guide:

<https://learning.candid.org/resources/nonprofit-startup-resources/>



FILING YOUR ARTICLES OF INCORPORATION



BUSINESS ENTITY SEARCH

I would like to Search By(enter information in one field be

Select One:

Entity Name:

Entity ID:

Principal Name: ☒ Individual ☐ Entity

Registered Agent Name: ☒ Individual ☐ Entity

Filing Number:

[Advanced Search Options](#)

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.



FILING YOUR ARTICLES OF INCORPORATION



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.



ARTICLES OF INCORPORATION PURPOSE

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.



ARTICLES OF INCORPORATION PURPOSE

- 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



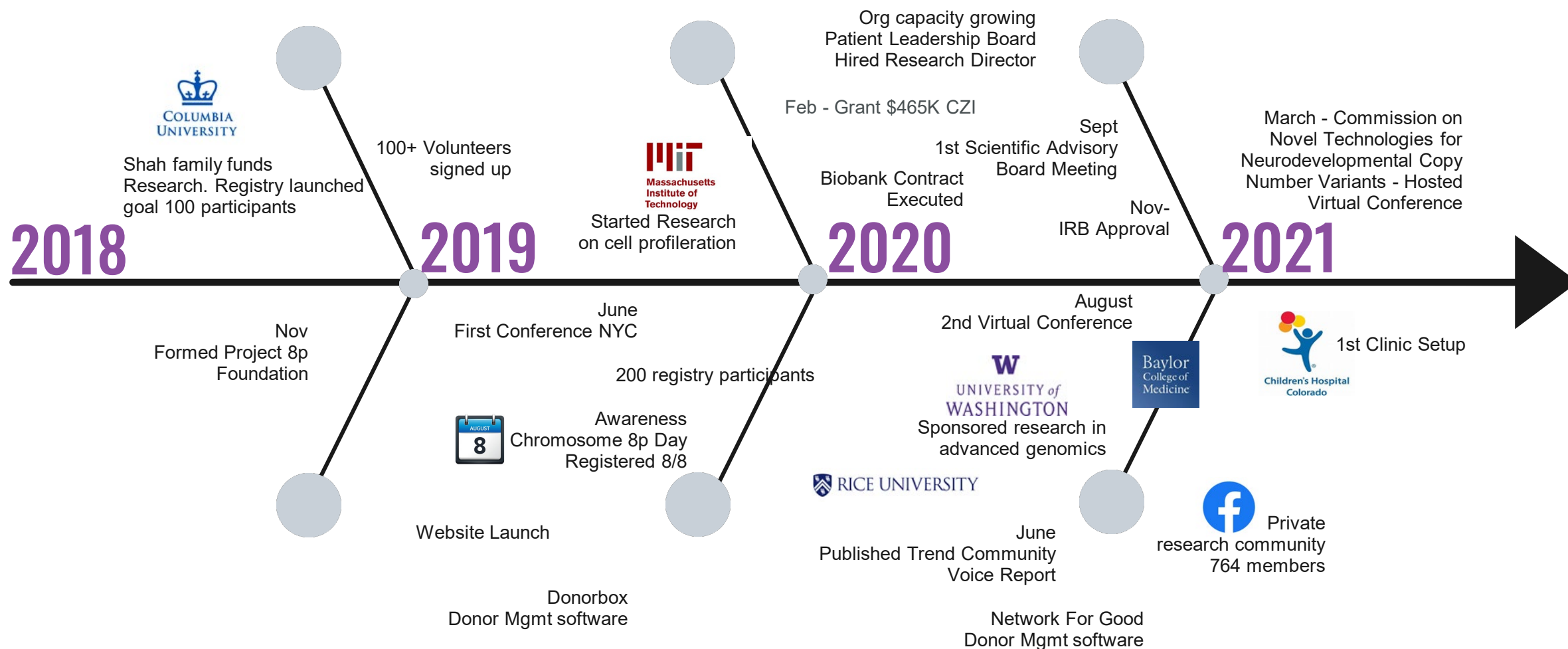
FIRST 8p CONFERENCE, 6 MONTHS AFTER FORMATION



from strangers to family



PROJECT 8p ACHIEVEMENTS IN 2 YEARS





VISION, MISSION, GOALS



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

Future State

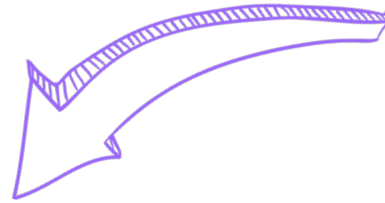
2025 press release

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

FEATURE REVIEW

Chromosome 8p as a potential hub for developmental neuropsychiatric disorders: implications for schizophrenia, autism and cancer

R Tabarés-Seisdedos¹ and JLR Rubenstein²

¹Teaching Unit of Psychiatry and Psychological Medicine, Department of Medicine, CIBER-SAM, University of Valencia, Valencia, Spain and ²Nina Ireland Laboratory of Developmental Neurobiology, Department of Psychiatry, University of California, San Francisco, CA, USA

Molecular Psychiatry (2009) 14, 563–589
© 2009 Nature Publishing Group All rights reserved 1359-4184/09 \$32.00
www.nature.com/mp



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



THE WHO? TEAM BUILDING



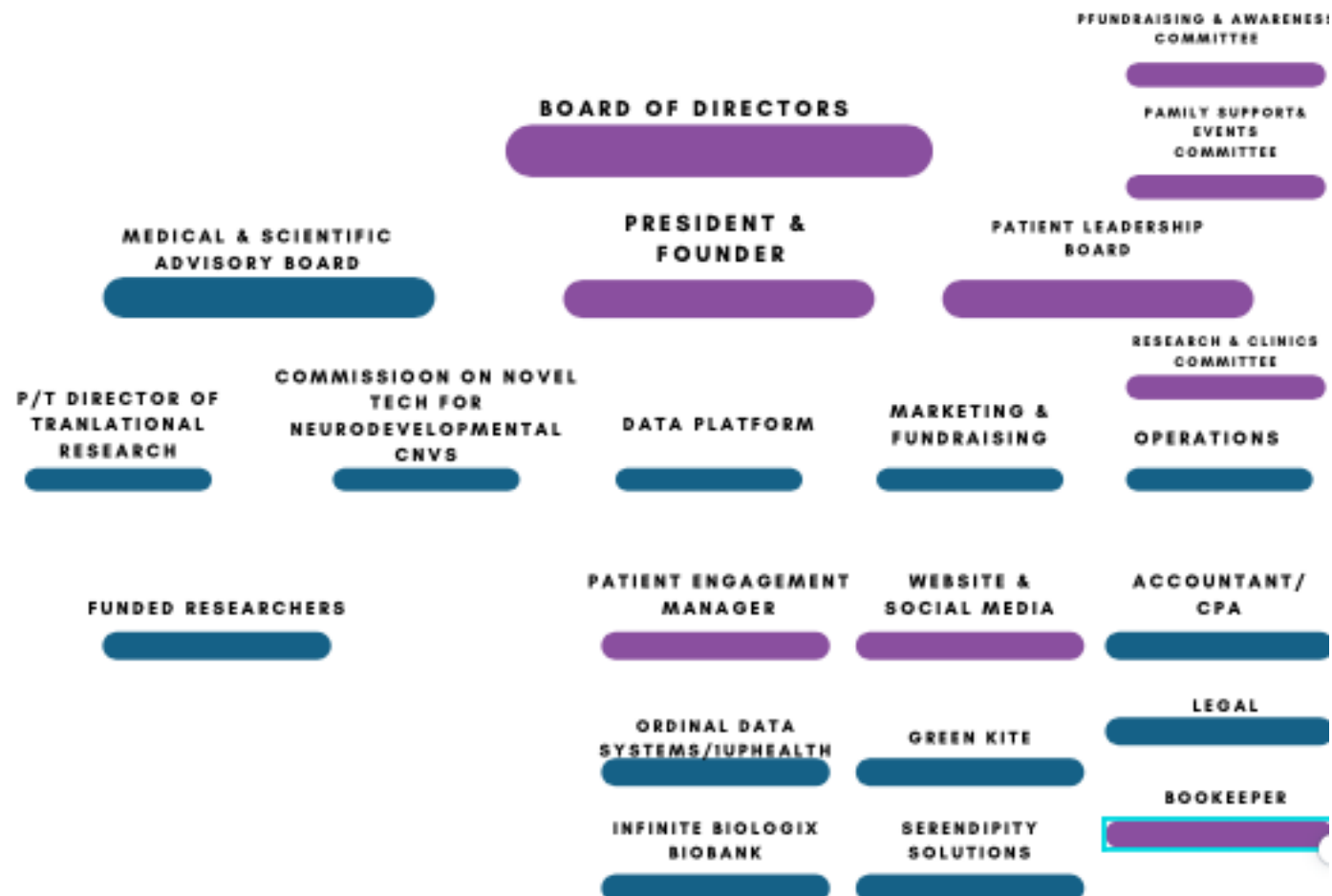
- Invest in People – Passionate and Proactive people who work well together
- Whomever you identify and recruit, your role as a leader is to keep everyone engaged closely connected to those affected and the mission.
- Don't start with titles. Think about the activities and responsibilities you want people 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.

- All of your stakeholders –
- Patients/Families in your community
- Doctors/Clinicians
- Researchers
- Funders
- Industry
- Regulators

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



8p ORGANIZATIONAL CHART



Thank you!

Contact me at bina@project8p.org
Bina Shah





“JUST RIGHT” BYLAWS FOR YOUR ORGANIZATION

Julie Raskin, MA
Executive Director
Congenital Hyperinsulinism International



ABOUT CONGENITAL HYPERINSULINISM INTERNATIONAL (CHI)

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.





PROSPECTIVE BOARD MEMBERS GATHERED TO BRAINSTORM ABOUT FOUNDING AN ORGANIZATION

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.



THANK YOU



Feel free to reach out:
Jraskin@congenitalhi.org





ABCs & 123s OF NONPROFIT FORMATION: WALKING THE PATH WITH OTHERS



NORD®
National Organization
for Rare Disorders

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

SS-4 Application for Employer Identification Number
(Rev. December 2019)
Department of the Treasury
Internal Revenue Service

OMB No. 1545-0003

EIN

1 Legal name of entity (or individual) for whom the EIN is being requested

2 Trade name of business (if different from name on line 1)

3 Executor, administrator, trustee, "care of" name

4a Mailing address (room, apt., suite no. and street, or P.O. box)

5a Street address (if different) (Don't enter a P.O. box.)

4b City, state, and ZIP code (if foreign, see instructions)

5b City, state, and ZIP code (if foreign, see instructions)

6 County and state where principal business is located

7a Name of responsible party

7b SSN, ITIN, or EIN

8a Is this application for a limited liability company (LLC) (or a foreign equivalent)? ☐ Yes ☐ No

8b If 8a is "Yes," enter the number of LLC members ☐ Yes ☐ No

8c If 8a is "Yes," was the LLC organized in the United States? ☐ Yes ☐ No

9a Type of entity (check only one box). **Caution:** If 8a is "Yes," see the instructions for the correct box to check.

<input type="checkbox"/> Sole proprietor (SSN)	<input type="checkbox"/> Estate (SSN of decedent)
<input type="checkbox"/> Partnership	<input type="checkbox"/> Plan administrator (TIN)
<input type="checkbox"/> Corporation (enter form number to be filed) ▶	<input type="checkbox"/> Trust (TIN of grantor)
<input type="checkbox"/> Personal service corporation	<input type="checkbox"/> Military/National Guard
<input type="checkbox"/> Church or church-controlled organization	<input type="checkbox"/> State/local government
<input type="checkbox"/> Other nonprofit organization (specify) ▶	<input type="checkbox"/> Farmers' cooperative
<input type="checkbox"/> Other (specify) ▶	<input type="checkbox"/> REMIC
	<input type="checkbox"/> Indian tribal governments/enterprises

Group Exemption Number (GEN) if any ▶

9b If a corporation, name the state or foreign country (if applicable) where incorporated

State	Foreign country
-------	-----------------

10 Reason for applying (check only one box)

<input type="checkbox"/> Started new business (specify type) ▶	<input type="checkbox"/> Banking purpose (specify purpose) ▶
<input type="checkbox"/> Hired employees (Check the box and see line 13.)	<input type="checkbox"/> Changed type of organization (specify new type) ▶
<input type="checkbox"/> Compliance with IRS withholding regulations	<input type="checkbox"/> Purchased going business
	<input type="checkbox"/> Created a trust (specify type) ▶
	<input type="checkbox"/> Created a pension plan (specify type) ▶



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 THINGS TO CONSIDER

- 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





THANK YOU

Let's connect if I can help!

Email: seth@ourodysey.org

Twitter/Instagram: [@srotberg15](https://twitter.com/srotberg15)





NORD®
National Organization
for Rare Disorders

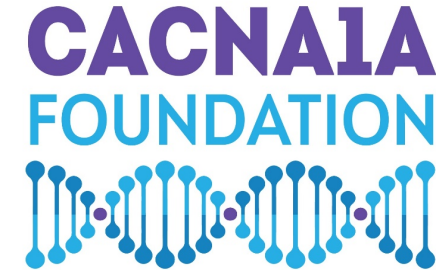
HOLDING YOUR ORGANIZATION'S INAUGURAL BOARD MEETING

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
 - › Quorum - 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.
 - *Roberts Rule of Order* – procedural guide
- Document the meeting
 - › Minutes should reflect the discussions/decisions
- Thank your board!



ROBERT'S RULES OF ORDER - Cheat Sheet for Nonprofits

<https://www.boardeffect.com/blog/roberts-rules-of-order-cheat-sheet/>

Action	What to Say	Can interrupt speaker?	Need a Second?	Can be Debated?	Can be Amended?	Votes Needed
Introduce main motion	"I move to..."	No	Yes	Yes	Yes	Majority
Amend a motion	"I move to amend the motion by...." (add or strike words or both)	No	Yes	Yes	Yes	Majority
Move item to committee	"I move that we refer the matter to committee."	No	Yes	Yes	No	Majority
Postpone item	"I move to postpone the matter until..."	No	Yes	Yes	No	Majority
End debate	"I move the previous question."	No	Yes	Yes	No	Majority
Object to procedure	"Point of order."	Yes	No	No	No	Chair decision
Recess the meeting	"I move that we recess until..."	No	Yes	No	No	Majority
Adjourn the meeting	"I move to adjourn the meeting."	No	Yes	No	No	Majority
Request information	"Point of information."	Yes	No	No	No	No vote
Overrule the chair's ruling	"I move to overrule the chair's ruling."	Yes	Yes	Yes	No	Majority
Extend the allotted time	"I move to extend the time by ____ minutes."	No	Yes	No	Yes	2/3
Enforce the rules or point out incorrect procedure	"Point of order."	Yes	No	No	No	No vote
Table a Motion	"I move to table..."	No	Yes	No	No	Majority



PURPOSE OF THE INAUGURAL MEETING



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



EVALUATION/REFLECTION



- 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



NORD®
National Organization
for Rare Disorders

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

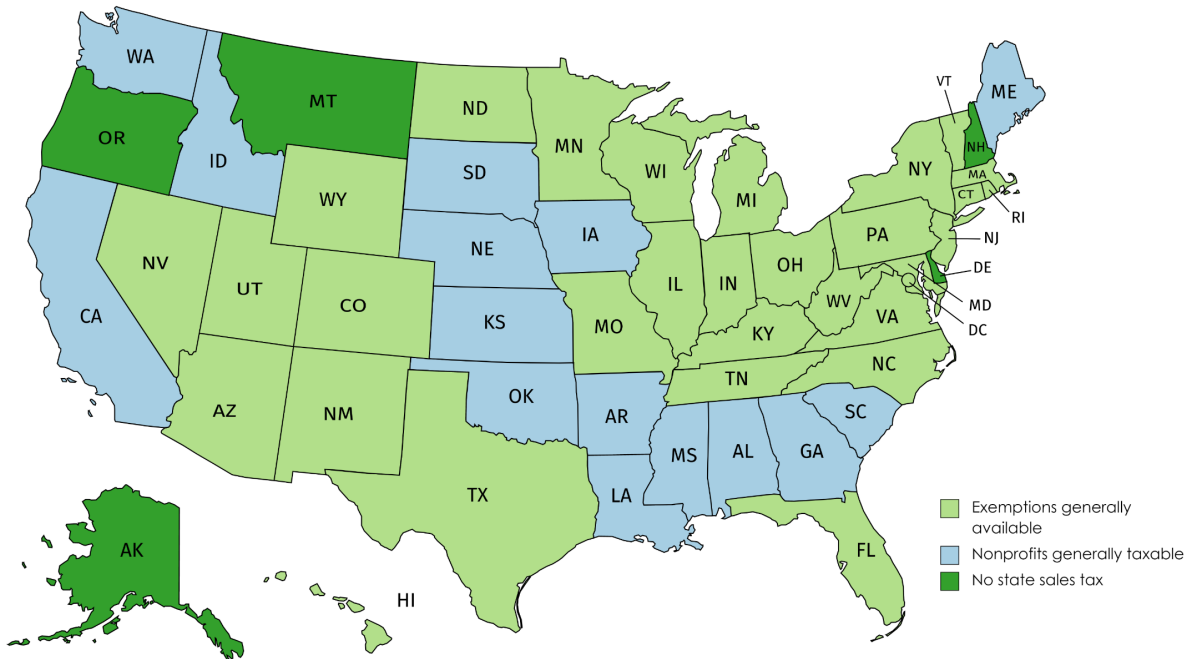


STATE REGULATION & TAXATION OF 501(C)(3) ORGANIZATIONS

- **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



Created with mapchart.net

- 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.

