



NORD[®]
National Organization
for Rare Disorders

Starting a Not-for-Profit Organization: You can do it, we can help!

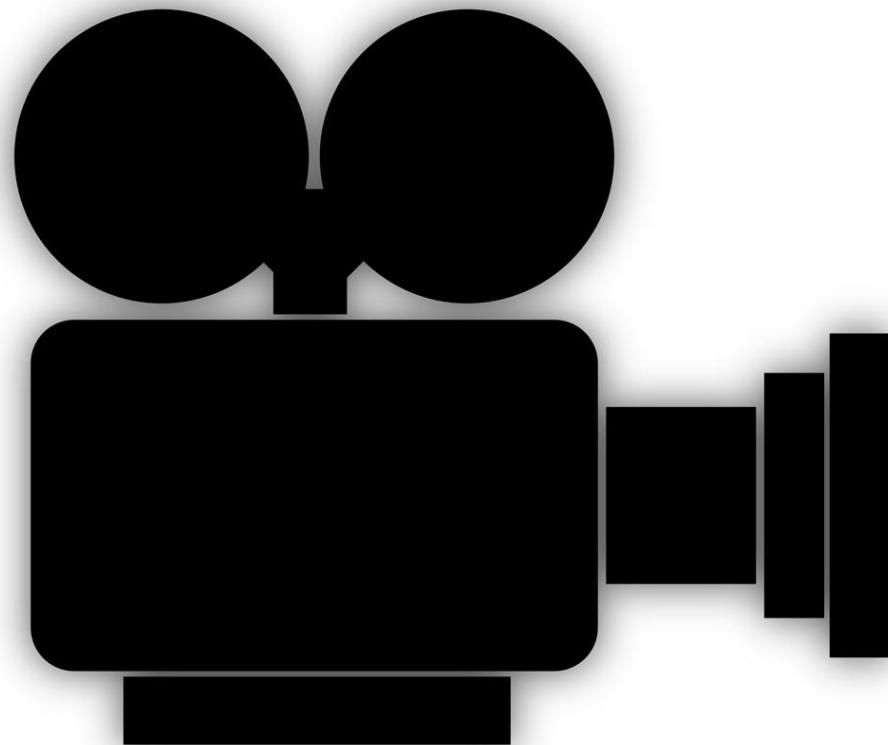
For sound, stream audio through your speakers.

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Alone we are rare. Together we are strong.[®]

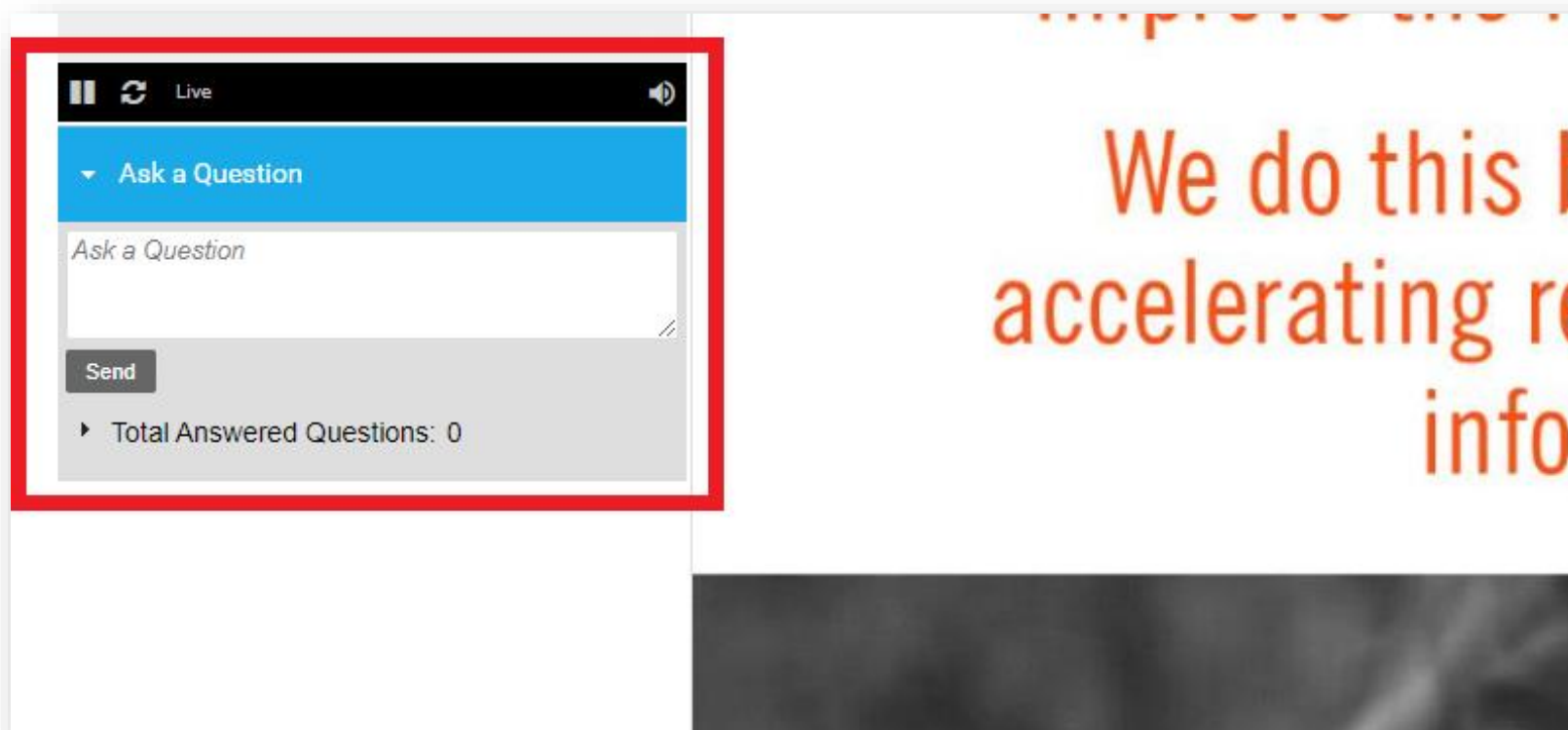


This webinar is being recorded.



Question and Answer Session

Submit your questions using the chat function. It can be found at the **left hand side** of the window.



NORD, an independent nonprofit, is leading the fight to improve the lives of **rare disease patients and families**.

We do this by supporting patients and organizations, accelerating research, providing education, disseminating information and driving public policy.



rarediseases.org

Notes & Updates

MAKE AN IMPACT ON RARE DISEASE DAY

**SHOW
YOUR STRIPES**



RARE DISEASE DAY

Learn more and find local events:

<https://rarediseases.org/rare-disease-day/>



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Notes & Updates



featuring The Rare Impact Awards®

CLEVELAND, OHIO
MAY 14-16, 2020

Learn more and register:
<https://rarediseases.org/living-rare-forum/>



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Speakers



Debbie Drell
Director of Membership
NORD



Jason Qu
Managing Attorney, Nonprofit and
Small Business Legal Assistance
Programs
D.C. Bar Pro Bono Center



Seth Rotberg
Co-Founder, Head of Strategy and
Engagement
Our Odyssey





Marcia Galan and her daughter, Alena, diagnosed with Mucopolysaccharidosis type VI (MPS VI)

Together We Can

A case study in the power of nonprofit advocacy

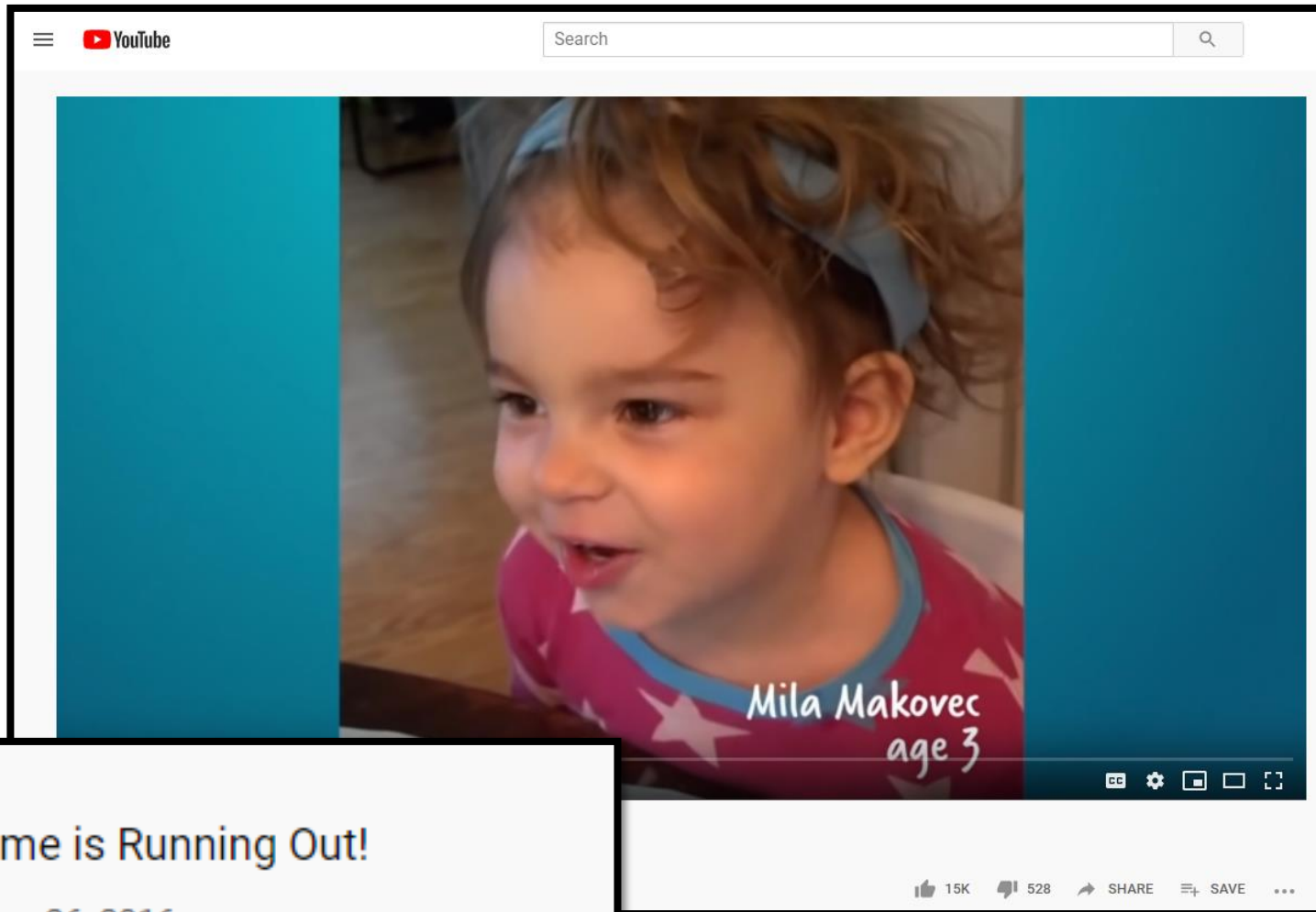
Debbie Drell

Director of Membership
NORD



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One in A Million...



#SavingMila

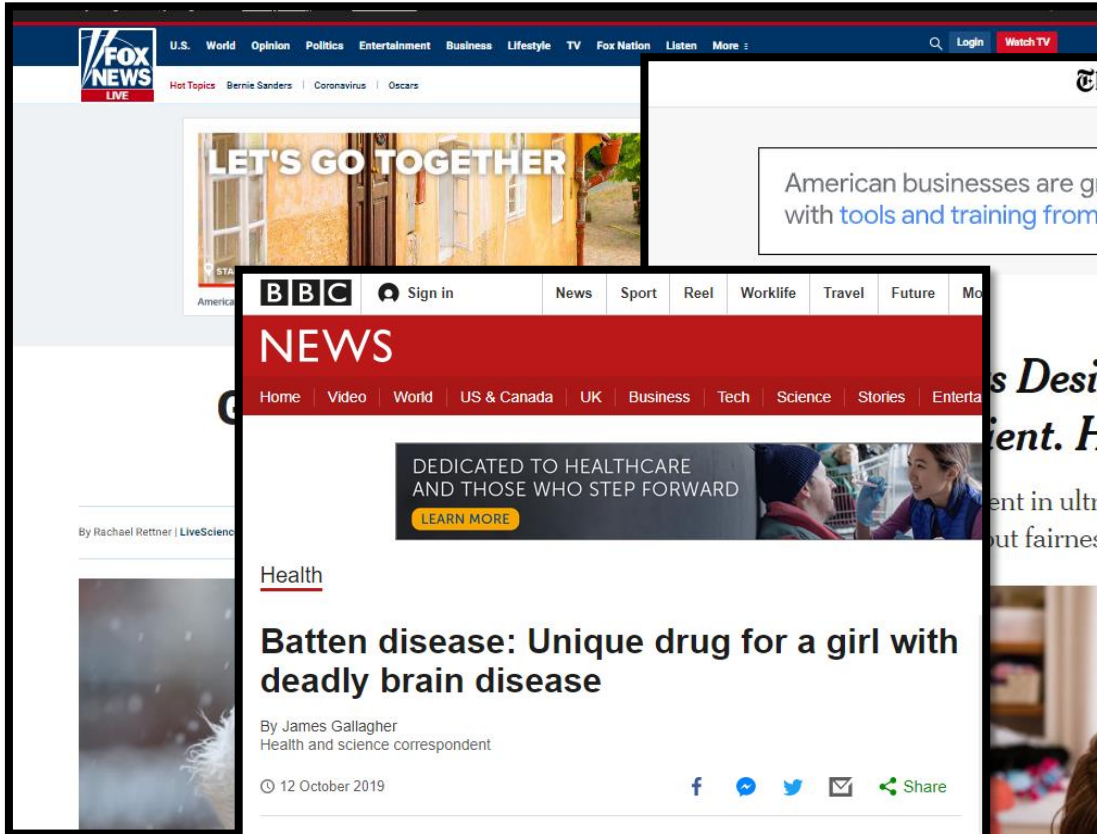
Saving Mila - Time is Running Out!

2,004,540 views • Dec 26, 2016



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Together We Can!



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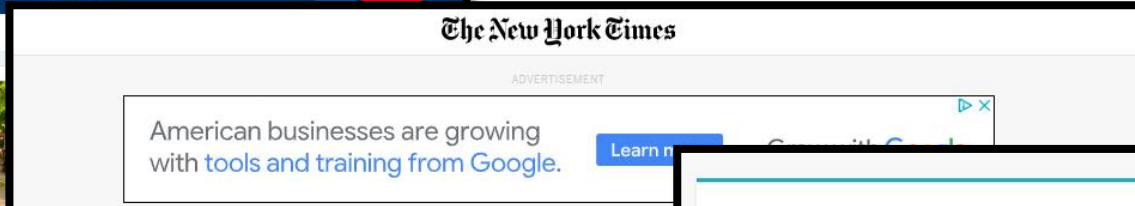
Health

Batten disease: Unique drug for a girl with deadly brain disease

By James Gallagher
Health and science correspondent

12 October 2019

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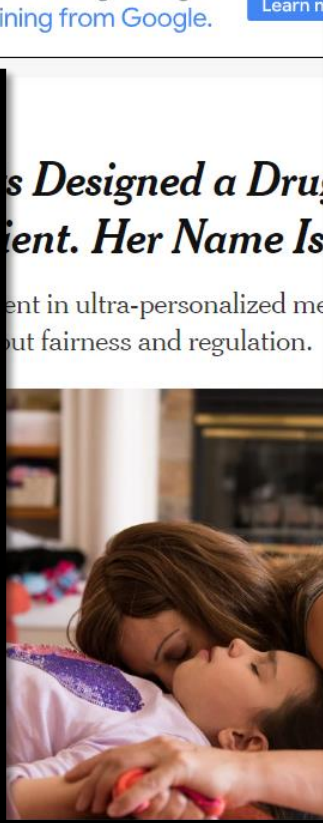
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Designed a Drug
Her Name Is

ent in ultra-personalized me
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BIOTECH

STAT+

After a bespoke therapy rescues a young girl, the FDA considers advance of individualized treatments

By MEGHANA KESHAVAN @megkesh / OCTOBER 9, 2019





Starting a 501(c)(3) Nonprofit: *Benefits, Limitations & Legal Requirements*

Jason Z. Qu
Managing Attorney
D.C. Bar Pro Bono Center

Vaughn family: Son, Morgan (left), diagnosed with Necrotizing Enterocolitis at four days old



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D.C. Bar Pro Bono Center – About Us

- We are a legal services organization based in Washington D.C.
- Nonprofit Legal Assistance Program: We match DC-based nonprofit organizations with pro bono legal counsel; host free in-person legal clinics to assist with common issues; and provide free education/training on real-world legal topics facing nonprofits
- We maintain a nonprofit legal library with webinars and print resources: www.probono.center/nonprofits



Background: Nonprofits and the Nonprofit Sector

- There are over 1.5 million registered nonprofits in the U.S.; the focus of today's webinar will be on 501(c)(3) public charities
 - Public charities account for approximately 2/3 of all registered nonprofits, and represent the quintessential nonprofit organization – operated exclusively for charitable/educational purposes
 - There are over 30 other types of tax-exempt nonprofit organizations (including private foundations, chambers of commerce, fraternal organizations, and civic leagues) - special rules apply, and are not the focus of today's session
 - 501(c)(3)s are afforded unique benefits and advantages, but they also come with significant operational demands & restrictions



Benefits and Advantages of Operating a 501(c)(3) Nonprofit

1. **Mission First**: 501(c)(3)s are legally required to pursue their tax-exempt mission – no legal imperative to generate revenue or satisfy shareholders; staff & board members are generally passionate, driven, and mission-aligned
2. **Tax Exempt**: 501(c)(3)s are generally exempt from paying income, sales, use, franchise, property, and other state, federal, and local taxes
3. **Donations Deductible**: Donations *to* 501(c)(3) orgs are also tax deductible for donors, creating a unique financial incentive to donate; this is a unique feature of (c)(3) organizations



Benefits and Advantages of Operating a 501(c)(3) Nonprofit (cont.)

4. **Dedicated Funding Sources**: In addition to tax-deductible donations from individuals, 501(c)(3)s are exclusively eligible for certain government grants, government contracts, grants from private foundations, grants from other public charities, and corporate sponsorships, co-ventures, and partnerships
5. **The 501(c)(3) Brand**: Donors, and the public at large, recognize and trust the 501(c)(3) brand; they expect transparency and accountability from 501(c)(3) entities because of state, federal, and private party oversight



Before You Start

Six Key Considerations for Nonprofit Founders



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1. Avoiding Duplication: Needs Assessment & Environmental Scan

- Nonprofits compete for funding, personnel, resources, board members, and clients/constituents – duplication is bad for your startup, and for the sector as a whole
 - Consider working within an existing nonprofit organization instead
- Perform a needs assessment – research, identify and describe the community you plan on serving & the specific needs or issues you plan on addressing
- Perform an environmental scan to understand the existing nonprofit landscape
 - Tools: candid.org (formerly Guidestar) – Catalog of Philanthropy – Google searches – issue area-specific resources/directories – talk to existing/allied organization
 - “Completing vs. competing” – if similar organizations exist, can you distinguish yourself/serve an underserved niche?



2. Business Planning

- Nonprofits are businesses – start-ups should create a detailed business plan to attract funders, partners, board members, and to help with their 501(c)(3) application
- A business plan will require you to articulate a financially sustainable model for your organization and to identify initial/prospective sources of funding; even all-volunteer organizations will have expenses and financial needs
- Components of a nonprofit business plan often include:
 1. Mission statement
 2. Description of specific programs
 3. Survey of existing nonprofit landscape/market research
 4. Leadership/personnel needs & assets
 5. Financial model, projections, & potential sources of funding
 6. Short and long-term growth plan
- NORD has many business planning resources (sample bylaws, sample conflict of interest policies, how to build a mission statement primer, etc.) under its RareLaunch program
 - Email rarelaunch@rarediseases.org to obtain copies of templates and resources

2. Business Planning (cont.)

- Business planning resources:
 - [SCORE](#)
 - [US SBA Business Plan Tool](#)
 - [DCRA Small Business Resource Center](#) (DC)
 - [Washington DC Small Business Center](#) (DC)
 - [Anacostia Economic Development Center](#) (DC)
 - Sample/template nonprofit business plans (available online)
- Note – these Resources will generally focus on for-profit entities; nonprofit-specific business planning resources are not as readily available, but can be adapted from for-profit models

3. Board Oversight/Shared Control

- The Board of Directors collectively determines the priorities and strategic direction of the organization, and is ultimately responsible for fiscal oversight – not the founder or the ED/CEO
- Board recruitment, retention, and management is an art – possibility of conflicts, factions, and dysfunction
 - On the other hand, good directors can perform vital functions and bring in critical expertise (e.g. financial, legal, programmatic, fundraising) and resources
- Founder(s) often choose the initial board members and can exercise a significant amount of control – founder may also serve as initial staff (e.g. first Executive Director) and make key management decisions
 - Nevertheless, founders do not have 100% control and can be outvoted or removed, especially as the board/organization grows
- Only start a nonprofit if you are comfortable with the concept of shared control & the demands of board management
- If you don't have board experience, recruit initial board members who do; avail yourself of educational resources: <https://www.lawhelp.org/dc/resource/serving-on-the-board-of-directors>

4. Limits on Political Activity

- Nonprofits are subject to limits/restrictions on their political activities:
- They can engage in an *unlimited amount* of issue advocacy
 - For example, advocating on public policy issues & on behalf of constituents, raising awareness, and/or educating the public and policymakers on specific topics
- They can engage in a *limited amount* of lobbying, defined as attempts to influence specific legislation (e.g. bills in Congress or at the state/local level)
 - Lobbying cannot be a “substantial part” of a nonprofit’s activities; under one common IRS test, can only be up to 20% of an organization’s total expenditures
 - Only lobbying if you’re attempting to influence actual legislation; other activities are unrestricted
 - E.g., engaging with administrative agencies/regulatory process is an unrestricted advocacy activity, not lobbying, since administrative agencies only implement existing legislation

4. Limits on Political Activity (cont.)

- There is a *blanket prohibition* on political intervention, defined as intervening in, or participating in, any political campaign on behalf of or in opposition to any candidate for public office
- If you would like to engage in political intervention or a substantial amount of lobbying, 501(c)(3) is not the best entity choice for you
 - 501(c)(4)s, 501(c)(6)s, and PACs are alternative options
- For more information, see our webinar:
<https://www.lawhelp.org/dc/resource/webinar-nonprofit-advocacy-101-lobbying-political-activity-and-irs-rules-for-501c3s?ref=06WII>

5. Initial Start-up Requirements and Costs

Incorporating and registering a 501(c)(3) is a multi-step process that requires a significant investment in time and money. Steps include:

- A. Recruiting incorporators and initial board members – should have at least 3
- B. Create a state-level nonprofit corporation by filing Articles of Incorporation with a state corporate registration agency
 - Agency may be the Secretary of State or other regulatory agency; see SBA website for information: <https://www.sba.gov/business-guide/launch-your-business/register-your-business>
 - Articles must contain IRS-required language in order to register the corporation as a 501(c)(3) – refer to template articles/[“Starting a Nonprofit” guide](#) for more information
 - Decide whether you will be a formal membership organization or a non-membership organization; non-membership organizations are more common and are easier to operate – they can still have “members”, but don’t play a formal governance role

5. Initial Start-up Requirements and Costs

- C. Draft bylaws – bylaws spell out the internal operating rules of the organization
 - Should address: election and tenure of directors; rules regarding board meetings (e.g. notice requirements, quorum, voting thresholds); appointment of officers (e.g. CEO, treasurer, etc.); creation of board committees; etc.
 - NORD’s RareLaunch program has templates
- D. Draft a Conflicts of Interest policy and other governance policies (e.g. whistleblower; record retention)
 - A COI policy is an instruction manual for how your organization navigates potential conflicts involving organizational decisions which impact the organization’s directors, officers, and key employees in their individual capacities
 - NORD’s RareLaunch program has templates
- E. Hold an inaugural board meeting to confirm directors, adopt the Bylaws and governance policies, elect officers, and conduct other start-up formalities

5. Initial Start-up Requirements and Costs

- F. Federal recognition – file IRS Form 1023 to “upgrade” organization from state-registered nonprofit to federally-registered 501(c)(3). 2 filing options:
- Form 1023-EZ: File if your organization’s projected annual gross receipts will not exceed \$50,000 in any of the next three years, and if its assets do not exceed \$250,000
 - Three-page form that asks for basic information on your organization and activities - filing fee is \$275
 - Form 1023: For organizations who do not qualify for 1023-EZ
 - 26-page, multi-part form that asks for detailed information on your organization and activities; requires detailed financial history information and/or financial projections for the next 3 years - filing fee is \$600
 - On both forms, filer must affirmatively opt into being classified as a “public charity” – default assumption is that 501(c)(3) organizations are “private foundations”, which enjoy less favorable tax status and have more financial restrictions
 - Processing time for 1023 applications vary significantly – between 4 weeks to 6 months

5. Initial Start-up Requirements and Costs

G. Apply for state tax exemptions and charity licenses

- Requirements vary by state, but new 501(c)(3)s will generally have to apply for a number of licenses and exemption certificates from their state of incorporation
- For example, DC nonprofits with over \$50,000 in gross receipts need to obtain a Basic Business License (filing fee: \$412.50) and apply for state tax exemptions from the Office of Tax and Revenue

6. Ongoing Governance & Administrative Requirements

Nonprofits are subject to ongoing filing & administrative requirements imposed by both the IRS and state regulators. Major requirements include:

- A. Annual IRS reporting
 - Nonprofits must file an IRS Form 990 on an annual basis
- B. Periodic state filings
 - Most states require periodic reports to maintain your corporate registration
- C. Applying for charitable solicitation licenses in other states, as needed
 - ~40 states have their own charitable solicitation registration requirements; fees and filing requirements vary by state
 - Nonprofits need to register in every state where they actively fundraise
- D. Ongoing board engagement & oversight
 - The Board of Directors should be engaged, meet regularly, and exercise its legally-mandated oversight functions (including strategic planning, financial review & oversight, and setting staff/executive compensation); board should observe corporate formalities and bylaws requirements (re: meeting minutes, meeting procedures, etc.)

6. Ongoing Governance & Administrative Requirements

E. Avoiding private inurement/conflicts of interest

- Nonprofit's financial assets cannot be used to unduly benefit private individuals, especially those who exercise control over the organization; ok to pay salary or for bona fide services, but must follow conflict of interest/executive compensation policies

F. Recordkeeping – keep records of all board meetings & all other records required by state and federal law

G. Fundraising and acknowledging donations – nonprofits should provide receipts to donors and note the value of any goods/services provided in exchange for donations

H. Day-to-day business operations

- Nonprofits are a business, especially mature orgs with facilities and staff. Common legal/compliance issues include:

Employment law obligations – hiring/firing/retaining, payroll, benefits, anti-discrimination/harassment...

Insurance and risk management – assessing and mitigating risk, waivers of liability, purchasing insurance...

Accounting and financial management – keeping and auditing financial records, tracking expenditures & revenue...

Questions?

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Washington, D.C. 20001
jqu@dcbar.org

Nonprofit Resources: www.lawhelp.org/dc/ced

“Starting a Nonprofit” resource collection:
<https://www.lawhelp.org/dc/resource/starting-a-nonprofit>

“Starting a Nonprofit in D.C.” guide (with links to template documents):
<http://www.lawhelp.org/dc/resource/starting-a-nonprofit-booklet/download/36E476B0-6336-45CE-8D9E-6F0B5E8CA905.pdf>

Starting a Not-for-Profit: Our Odyssey

Seth Rotberg

Co-Founder, Head of Strategy & Engagement
Our Odyssey

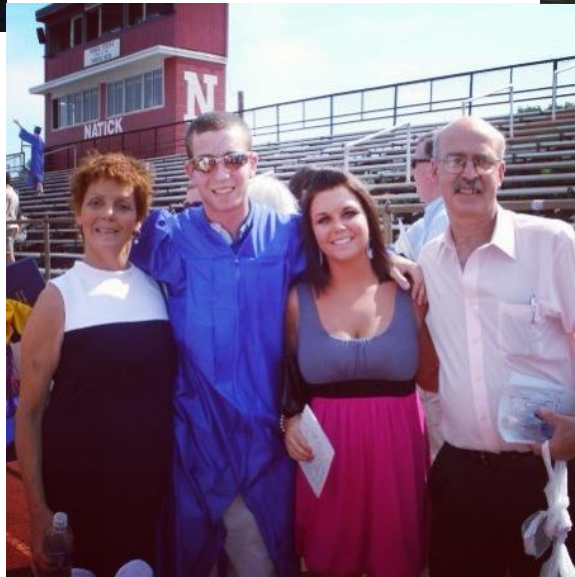


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Madilyn Yang (far left) has been battling a rare breathing disorder since birth called Central Congenital Hypoventilation Syndrome (CCHS) or Ondine's Curse.

How Rare Disease Impacted My Family



Connecting to the Rare Disease Community



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Nonprofit Management Degree

What I learned in grad school

- Fundraising and Development
- How to gather and analyze data
- Needs assessment turned into a consulting report
- Strategic planning
- How to negotiate



HUNTINGTON'S DISEASE
YOUTH ORGANIZATION



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Unmet Needs for Young Adults

- Speaking with your colleagues
- Is anyone else supporting these needs?
- Distinguishing your own needs from the community needs



Becoming a 501(c)(3) Nonprofit

1. Name your nonprofit
 1. Lock in a domain and website
2. Develop a Board of Trustees
3. By-laws, conflict of interest confidentiality
4. Articles of Incorporation
5. 501(c)(3) application
6. Finding a bank

1. Programs and services
2. Funding
3. Strategic plan
4. Volunteers



**OUR
ODYSSEY**



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Nonprofit Tips

How to identify core volunteers and a Board of Trustees



Thank You



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@_OurOdyssey_



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seth@ourodysey.org



www.OurOdyssey.org



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Question and Answer Session

Vaughn family: Son, Morgan (left), diagnosed with Necrotizing Enterocolitis at four days old



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Our presenters will answer them in the order in which they came in and based on relevance to the discussion.





Thank you.



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