



NORD[®]
National Organization
for Rare Disorders

RARELAUNCH: FORMING A FOUNDATION

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YOU'RE A 501(C)(3) — NOW WHAT?

- What is a strategic plan?
- Share the HOUSE MODEL
- Mission
- Three Pillars
- Infrastructure
- Real Life Experience

WHAT IS A STRATEGIC PLAN?

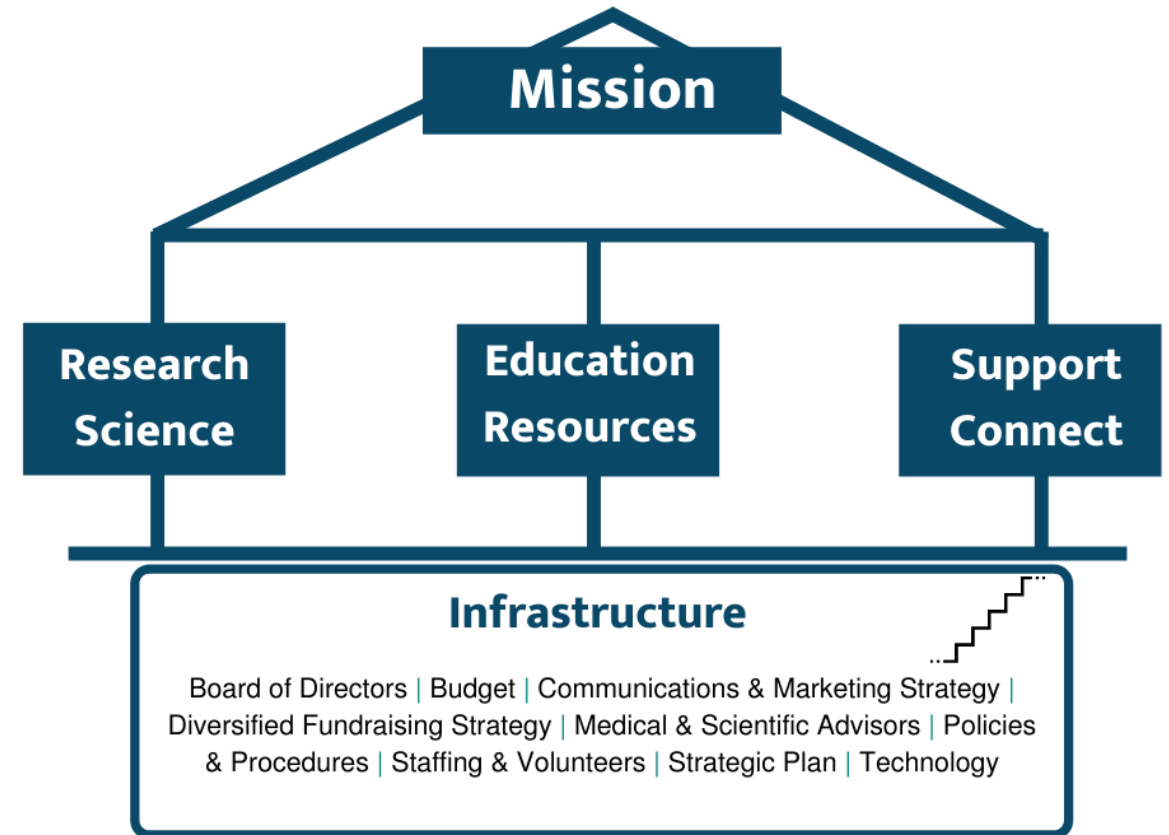


- Organization roadmap
- Simple or complex...or somewhere in between?
- Who develops the plan?
- When should a plan be implemented?
- How long should the plan be?
- Is it written in stone?
- What happens if we don't succeed?



HOUSE MODEL OUTLINE

- Peak of the Roof
- Three Pillars
- Basement/Foundation





MISSION & BELIEF STATEMENTS

- Mission Statement: Successes and Pitfalls

According to Top NonProfits®
CLEAR. Use simple language at a 8-10 grade reading level.
CONCISE. No fluff. Aim for 5- 14 words, 20 max.
USEFUL. Inform, focus, guide.

- Belief Statements – We believe that...

- Patients
- Caregivers
- Science
- Organization

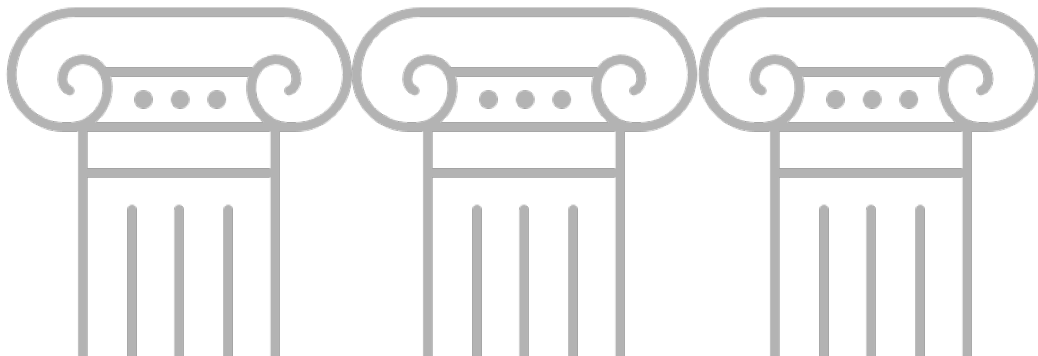
- Vision & Values



ORGANIZATIONAL PILLARS



- Research/Science
 - Develop program based on capacity
 - Communicate progress, discoveries, findings to entire organization constituency
- Education/Resources
 - Be the leading authority of information, resources and facts on your disease/condition
 - Deliver easily understandable, medically-reviewed content and value to patients, community physicians and the public
- Support/Connect
 - Be the “soft place to land” when newly-diagnosed, alone, feeling frustrated, etc.
 - Facilitate personal interactions, host regional meetings, national patient conference





INFRASTRUCTURE: BOARD OF DIRECTORS



KEY POINTS

- Bylaws – Adopted and Filed
 - Term limits/Positions
 - Manner of Acting
 - Transparency
- Job description
 - Governing or working board
 - Rules & Guidelines
 - Expectations/Accountability
- Recruitment
 - Rule of thirds (affected, med, influence)
 - Skills, experience, demographics

REAL-LIFE EXPERIENCE

- Bylaws matter! Make sure your bylaws are reviewed every five years, and that you are not out of compliance with term limits, requirements for Board of Directors, insurance, etc.



KEY POINTS

- Philosophy – Revenue dictated by expenses or expenses dictated by revenue?
- Necessary for goalsetting, transparency, measurement
- Categorize Revenue & Expense Line Items
 - Rev: Appeals, Special Events, Research, Grants, etc.
 - Exp: Events, Research, Payroll, Office Admin, etc.
 - Restricted & Unrestricted
- Keep an eye on expense allocation:
 - Program/Services
 - Fundraising
 - Administrative

REAL-LIFE EXPERIENCE

- When is the time to start using a budget for my emerging organization? NOW!



KEY POINTS

- Management and operations
- Messaging/Content creation
- Donor engagement/chain of touches
- Community/Volunteer engagement
- Website
- Social media
- Newsletter
- E-News blasts
- Calendar

REAL-LIFE EXPERIENCE

- Are you communicating using the platforms your constituents use?



KEY POINTS

- Donors want to know how their gift is making a difference
- Good stewardship of the funds
- Do not spend time or energy on quick fixes
- Grants
- Individual giving
- Special events
- Board of Directors
- Categorize then personalize
- Recurring gifts

REAL-LIFE EXPERIENCE

- Donor communication matters. Send impact report and other “proof of service” communications to donors frequently—not ONLY when you ask for donations!



INFRASTRUCTURE: MEDICAL & SCIENTIFIC ADVISORS

KEY POINTS

- Identify and recruit
- Job description/Transparency
- Disease symptom representation
- Term limits
- Guiding advisory board

REAL-LIFE EXPERIENCE

- Maintain boundaries to help structure the relationship with Medical and Scientific Advisors.



INFRASTRUCTURE: POLICIES & PROCEDURES



KEY POINTS

- Develop over time; proactive vs. reactive
- Basics:
 - Conflict of Interest
 - Financial Reserves Policy
 - Privacy Policy (website)/Understanding of GDPR compliance
 - Non-discrimination Policy
 - Organizational Effectiveness Policy
- When (if) Employees: Whistleblower Policy, Employee Manual (PTO, Vacation, Maternity)
- Reference the National Health Council's 38 Standards of Excellence

REAL-LIFE EXPERIENCE

- Use the policies that you have with the support of your Board to manage crises (they will happen).



INFRASTRUCTURE: VOLUNTEERS & STAFFING



KEY POINTS

- Volunteers
 - Recruitment beyond the board, grassroots, boots on the ground
 - The 3 C's: casual, connected, committed
 - Volunteer Engagement/Help One-Sheet
 - Committees
- Staffing

REAL-LIFE EXPERIENCE

- Use volunteers when you're a "virtual" org; your 501(c)(3) status allows you to do that!



KEY POINTS

- Constituent Relationship Management (CRM)
- A must—coding of relationships to your org
 - Affected/Household
 - Medical Professional
 - Relative
- Integration

REAL-LIFE EXPERIENCE

- Find what works for you and your volunteers/staff. Sometimes the most robust CRM isn't the best for every organization.

Thank you.



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