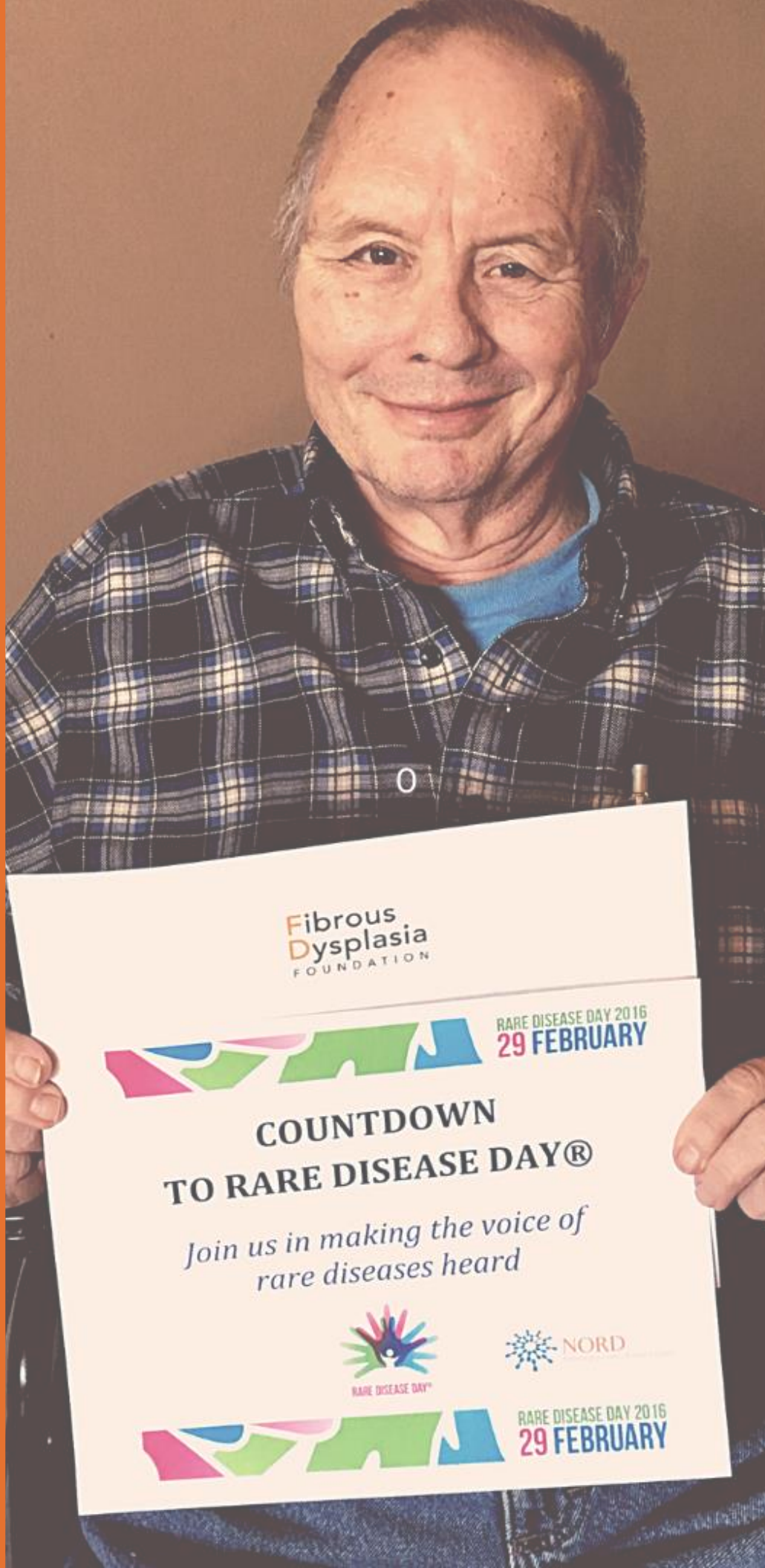
FD/MAS
ALLIANCE

2025-2027
Strategic Plan



Prepared by: Spur Local

Our Mission

The FD/MAS Alliance (incorporated as the Fibrous Dysplasia Foundation) is a community-driven 501c3 nonprofit that fosters the development of evidence-based treatments for Fibrous Dysplasia and McCune-Albright syndrome (FD/MAS). We **advance research**, **provide education** and **channel the voices of individuals and caregivers with FD/MAS**.

Process

The strategic plan was created over the course of a year by Spur Local and FD/MAS's Strategic Planning Committee, comprised of staff and board members. Throughout the process, community partners, physicians, researchers, patients and caregiver's perspectives were centered. This plan builds on the organization's previous successes and sets exciting goals for the next three years.

Strategic Goals

1 Diversify patient support and education.

2 Raise awareness of FD/MAS and the FD/MAS Alliance.

3 Strengthen the internal capacity of the organization.

4 Increase and diversify funding sources.

2025-2027

Diversify Patient Support and Education

The FD/MAS Alliance is dedicated to expanding its patient education and support services, ensuring that we reach a broader and more diverse segment of the FD/MAS community. By creating accessible, patient-centered materials and leveraging multiple platforms for engagement, we will strengthen our connection to those we serve.

Objectives

- Update communication efforts to link patient priorities to the research goals and research being conducted.
- A social media audit of FD/MAS will be conducted and then a plan for growth will be made.
- Patient materials will be reviewed with an emphasis on adding content representing underserved segments.
- Determine a regular schedule for the FD/MAS conference (annual or bi-annual) with a conference plan by the beginning of each year.
- Additional support group options will be explored, including a quarterly “meet and greet” option.

Metrics

- **15% growth in social media audience,** with a 20% growth in our Facebook group, by the end of the plan.
- **10% increase in patient resources available,** with new resources tailored to diverse patient needs within the first two years of the plan.
- **20% increase in views and downloads of patient education materials** by the end of the plan.
- The launch **of two new support groups** by the end of the plan.

Raise Awareness of FD/MAS and the Alliance

The FD/MAS Alliance recognizes the importance of raising awareness both within the medical and research communities and among the general public. By increasing the visibility of our work and the conditions we represent, we aim to drive greater recognition, funding, and support for our mission.

Objectives

- The Alliance will expand its involvement with broader advocacy groups (e.g., Global Genes).
- Increase advocacy with federal research authorities (e.g., FDA Rare Disease Innovation Hub).
- Expand the Alliance's presence at regional and national conferences through speaking or leadership roles (e.g., speakers' bureau).
- Expand use of the FD/MAS registry through partnerships in our field.
- Grant awardees will be asked to mention the Alliance in formal communications.
- Partnerships with academic institutions, hospitals, and medical professionals will be strengthened to share content more broadly.

Metrics

- By the end of the plan, FD/MAS will **increase their email mailing list by 10% and their social media audience by 15%.**
- **10% annual increase in FD/MAS conference registrations** year over year.
- **Six external events** featuring a FD/MAS speaker annually, by the last year of the plan.
- **Five partnerships** to disseminate FD/MAS content more broadly by the end of the year.

Strengthen Internal Capacity

To ensure we meet the growing needs of the FD/MAS community, the Alliance is committed to enhancing its internal capacity. This includes not only increasing staff and volunteer resources but also fostering stronger collaboration across our leadership and advisory boards. By doing so, we will be able to operate more efficiently and expand our impact.

Objectives

- Specifically skilled individuals will be recruited as non-voting board members to add capacity to committees.
- Strengthen communication and alignment between the Governing Board and the Scientific and Medical Advisory Councils.
- Time tracking for current administrative, fundraising, and operations work.
- Fundraising capacity will be added, potentially through a part-time or full-time role.
- Volunteers, contractors, or expanded staff will increase operations and administrative capacity.
- Focused recruitment of skilled volunteers.

Metrics

- Recruitment of **four new board members,** voting or non-voting, within the first two years of the plan.
- **An annual meeting** between the Governance Board and the Scientific and Medical Advisory Councils to ensure strong collaboration.
- **20 hours of additional capacity added to the staff for fundraising efforts monthly** by the last year of the plan.

Increase and Diversify Funding Sources

The sustainability of the FD/MAS Alliance is paramount to continuing its mission. To that end, the organization is committed to expanding and diversifying its funding base, ensuring that resources are available to meet the evolving needs of the FD/MAS patient community. By enhancing our internal fundraising operations, forging new relationships with donors, and exploring innovative funding mechanisms, we aim to secure a stable financial future.

Objectives

- The board will receive fundraising training and fundraising will be a permanent item of the board's meeting agenda.
- Personal stewardship efforts will increase, ensuring that every middle-level or higher donor receives personalized communication to build stronger relationships and trust.
- Research into new institutional funders, with new sources being asked for support regularly.
- A peer-to-peer fundraising campaign will be explored and launched if appropriate.
- FD/MAS will explore fee-for-service programs.
- FD/MAS will continue to prioritize our research goals.

Metrics

- **10% annual growth** in revenue.
- At least **two new institutional partners will be solicited every six months**.
- **Three new institutional funders secured** in first two years of the plan.
- **15 gifts of $10,000+ secured** across the plan.
- **10% new grant approval rate** by the last year of the plan.
- **50% donor retention rate** by the last year of the plan.
- **100% board members personally contributing and involved in at least one fundraising activity** annually.

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www.fdmasalliance.org