INTERNATIONAL
FOXP1
FOUNDATION

2024-2027
STRATEGIC PLAN

FROM OUR BOARD *of directors*

On behalf of the International FOXP1 Foundation Board of Directors, it is our pleasure to present you with our 2024 - 2027 Strategic Plan. This plan outlines our strategic vision for the next three years as we continue in our mission to build a global community that empowers and supports families and individuals with FOXP1 syndrome by sharing knowledge, inspiring hope, supporting research, and raising awareness.

With our mission in mind, we have created our first strategic plan. In this document, we aim to clearly articulate what the organization stands for, what our goals for the future are, and how we plan to hold ourselves accountable by measuring and communicating our progress.

Yours truly,
The International FOXP1 Foundation Board of Directors

About Us

The International FOXP1 Foundation is a registered 501(c)3 non-profit organization that is managed by parent volunteers. We are committed to supporting those who have been impacted by a FOXP1 diagnosis and to establishing regular venues for fundraising in an effort to guide and support research into FOXP1 syndrome and possible treatments.

Since our inception in 2019, our growth has been fueled by the tireless efforts of volunteers. Some of the founding board members met at the first in-person family conference hosted by the Seaver Autism Center for Research & Treatment at the Mt. Sinai School of Medicine in New York in June 2019. From there, Co-Presidents Adam Geller and Karl Whitney put a call out to the wider community to help set up a board of directors. Since late 2019, the International FOXP1 Foundation has been very fortunate to count on these founding members, along with numerous volunteer ambassadors, helpers, advisors, and donors, who collectively have helped bring us to this exciting inflection point.

Our mission is to build a global community that empowers and supports families and individuals with FOXP1 syndrome by sharing knowledge, inspiring hope, supporting research, and raising awareness.

Our vision is that every individual with FOXP1 syndrome will have the opportunity to reach their full potential and lead a productive and rewarding life.

Our STRATEGIC OBJECTIVES

The International FOXP1 Foundation's strategic vision for 2024 - 2027 consists of four strategic objectives. These objectives were identified with our mission and vision statements in mind and by asking the FOXP1 community what matters most to them. We feel that these four pillars not only honor our mission and vision, but reflect what the community feels is most important for us to focus on. These pillars will help to guide our organizational priorities for the next three years and are laid out in detail on pages 7-12.

1 Research

Accelerate research in FOXP1 syndrome through funding mechanisms, community engagement, data collection, awareness, and partnerships

2 Support

Support and empower the FOXP1 community across the globe

3 Community Building

Foster relationships between families, engage stakeholders, and increase opportunities for families to get involved

4 Information Sharing

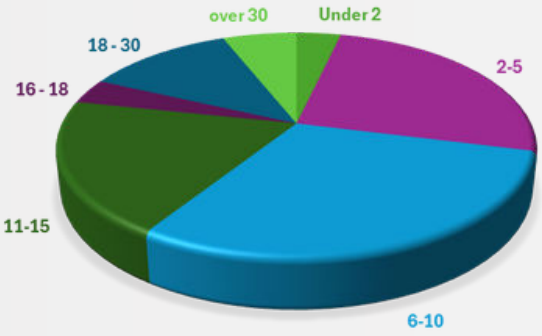
Facilitate knowledge-sharing and ensure that the FOXP1 community is kept up-to-date on research, advocacy, and support opportunities

For each pillar, key measurable goals have been defined. The International FOXP1 Foundation's Board of Directors will define priorities and activities to achieve these goals and report progress on an annual basis.

What Matters Most TO THE COMMUNITY

In order to better understand how we can build onto our existing programs and initiatives, we asked the international FOXP1 community what matters most to them. High-level results of a community needs assessment are provided below. This feedback informed our strategic planning process and similar outreach to the community in the future will continue to inform the work we do for years to come.

AGES OF INDIVIDUALS WITH FOXP1 REPRESENTED



Findings

TOP THREE RESPONSES FROM CATEGORIES RELATED TO "WHAT FAMILIES WANT / NEED"

RESOURCES FAMILIES WISH THEY HAD WHEN FIRST DIAGNOSED

70% Information about what to expect about the disorder

65% A packet of information about the disorder

58% Resources from my physician / care team / genetics

PROGRAMS/SERVICES FAMILIES WANTED WHEN FIRST DIAGNOSED

61% Meet-ups with other FOXP1 families

53% Behavioral support for my child

46% Educational opportunities such as conferences or webinars

PROGRAMS FAMILIES WISH THEY HAD RIGHT NOW

71% Meet-ups with other FOXP1 families

63% Behavioral support for my child

42% Caregiving / direct support

TOP FIVE PROGRAMS FAMILIES WOULD LIKE THE INTERNATIONAL FOXP1 FOUNDATION TO OFFER

1. Family retreats
2. Regional Meetings
3. Lobbying & Advocacy Initiatives
4. Mentorship Program
5. Caregiving / Respite

These are some of the data that informed the four strategic objectives that were identified earlier and are laid out in the next few pages in detail. Each strategic objective includes multiple key measurable goals for what the International FOXP1 Foundation strives to achieve over the next three years.

Our Current Position

After the four strategic objectives were identified, we assessed the current initiatives to better understand how they fall into each of these pillars. We "took stock" of the programs and services we currently offer, which will help to provide a foundation for us to build upon. Note: some initiatives support and are listed under multiple pillars.

CURRENT EFFORTS (AS OF MAY 2024)

Research

- Consultation with Scientific Advisory Board
- Supporting scientific research through
  - Direct funding
  - Letters of support
- Linking community to research
- Encouraging community research participation through RARE-X data collection program and other research projects
- Convening a research conference
- Monitoring research and literature
- Maintaining and supporting research collaborations

Community Building

- Strong social media presence
- In-person meetings
- International family gathering
- Monthly zooms
- International FOXP1 Foundation "open house"

Support

- Zoom meetings
- In-person meetings
- Facebook & social media
- Community connections

Information Sharing

- Monthly newsletter
- Social media presence
- International FOXP1 Foundation website
- Zoom meetings
- Annual online "open house"
- Notices of new research opportunities
- Research information disseminated to the community

Research

Accelerate research in FOXP1 syndrome through funding mechanisms, community engagement, data collection, awareness, and partnerships.

KEY GOALS

1. Analyze the landscape of FOXP1 research to understand gaps and opportunities that will guide the International FOXP1 Foundation's research plan

2. Increase research opportunities and funding mechanisms that will help to accelerate the pace of research in FOXP1 syndrome

3. Encourage and empower FOXP1 families to participate in research opportunities such as data collection efforts and observational or interventional clinical research studies

4. Conduct an observational ("natural history") study of FOXP1 syndrome to inform and expedite future clinical trials

5. Host a research symposium every two years that will encourage collaborations, spark new ideas, and generate enthusiasm

Support

Support and empower the FOXP1 community across the globe.

KEY GOALS

1. Provide various forms of social support to all individuals affected by FOXP1 syndrome

2. Expand international outreach so families across the globe feel empowered and supported regardless of where they live

3. Develop and measure programs aimed at newly diagnosed families, mentors, and ambassadors

4. Welcome and support newly diagnosed families and provide them with tools that will help them navigate the diagnosis of FOXP1 to help their loved one reach their full potential in life

Community Building

Build community, engage stakeholders, and increase opportunities for families to get involved in the International FOXP1 Foundation and community.

KEY GOALS

1. Increase opportunities for families to connect with one another through regional in-person meet-ups and international zoom chats

2. Host a global in-person meet-up every two years with a goal of increasing attendance by 20 percent bi-annually

3. Increase outreach and find more FOXP1 families by working with clinical centers of excellence, medical organizations, genetic testing companies, and other organizations

4. Expand the current ambassador program and create a new "buddies" program to help facilitate new relationships between families

Information Sharing

Ensure that the FOXP1 community is kept up-to-date on research, advocacy, clinical information, and engagement opportunities.

KEY GOALS

1. Develop printed materials that help to explain and communicate FOXP1 syndrome to families, doctors, and educators

2. Distill scientific information that is easy to understand for families that will keep them updated on the latest scientific research

3. Refresh the International FOXP1 Foundation website and make it easier to find critical resources such as FOXP1 syndrome summaries, scientific literature, upcoming and past events, etc.

4. Increase social media presence and diversify information-sharing on multiple platforms to connect with the community wherever they congregate

Sustainability Goals

The International FOXP1 Foundation understands that in order to meet our strategic goals, it is critical that we set ourselves up for long-term success. The following five categories reflect our sustainability initiatives to help us achieve our goals.

1. Grow capacity and bandwidth of the organization by increasing staff, volunteers, and consultants as a "force multiplier" to achieve our strategic priorities more efficiently in less time

2. Clearly define organizational roles; develop an organizational chart that clarifies board duties, committees, and volunteer roles

3. Increase volunteer opportunities and engage community members across the globe and harness talents across our membership

4. Diversify funding opportunities and implement financial strategies to keep the organization fiscally healthy

5. Create a succession plan to ensure that the organization continues to run smoothly through transitions and to prepare the next generation of Foundation leaders

Capacity Building

To sustain our strategic objectives, the International FOXP1 Foundation also needs to set ourselves up for success by building capacity. Capacity building will help us develop and strengthen our skills and programs while increasing resources that will help our organization succeed.

1

Hire Paid Staff

Paid staff often bring specialized skills and expertise that can significantly benefit a group like the International FOXP1 Foundation. Staff also helps to increase consistency, reliability, commitment, and accountability, and frees up the board of directors to govern and focus on the "big picture"

2

Improve Operations, Efficiencies & Best Practices

Efficient operations include clearly defining roles, streamlining processes, establishing working committees, and more. These organizational tactics will allow us to maximize our efficiencies, ensuring that funds, time, and other resources are used effectively to advance our mission. By doing this, we can make a bigger, more meaningful difference in the FOXP1 community. Improving efficiencies also creates a foundation for scalability and growth and helps to build trust and credibility with our community

3

Increase Volunteer Opportunities

Increasing our volunteer pool and creating new, meaningful volunteer opportunities can help us to accomplish more tasks in less time, thereby increasing the organization's overall capacity to serve our mission. Volunteers can also bring fresh perspectives and innovative ideas to the organization

4

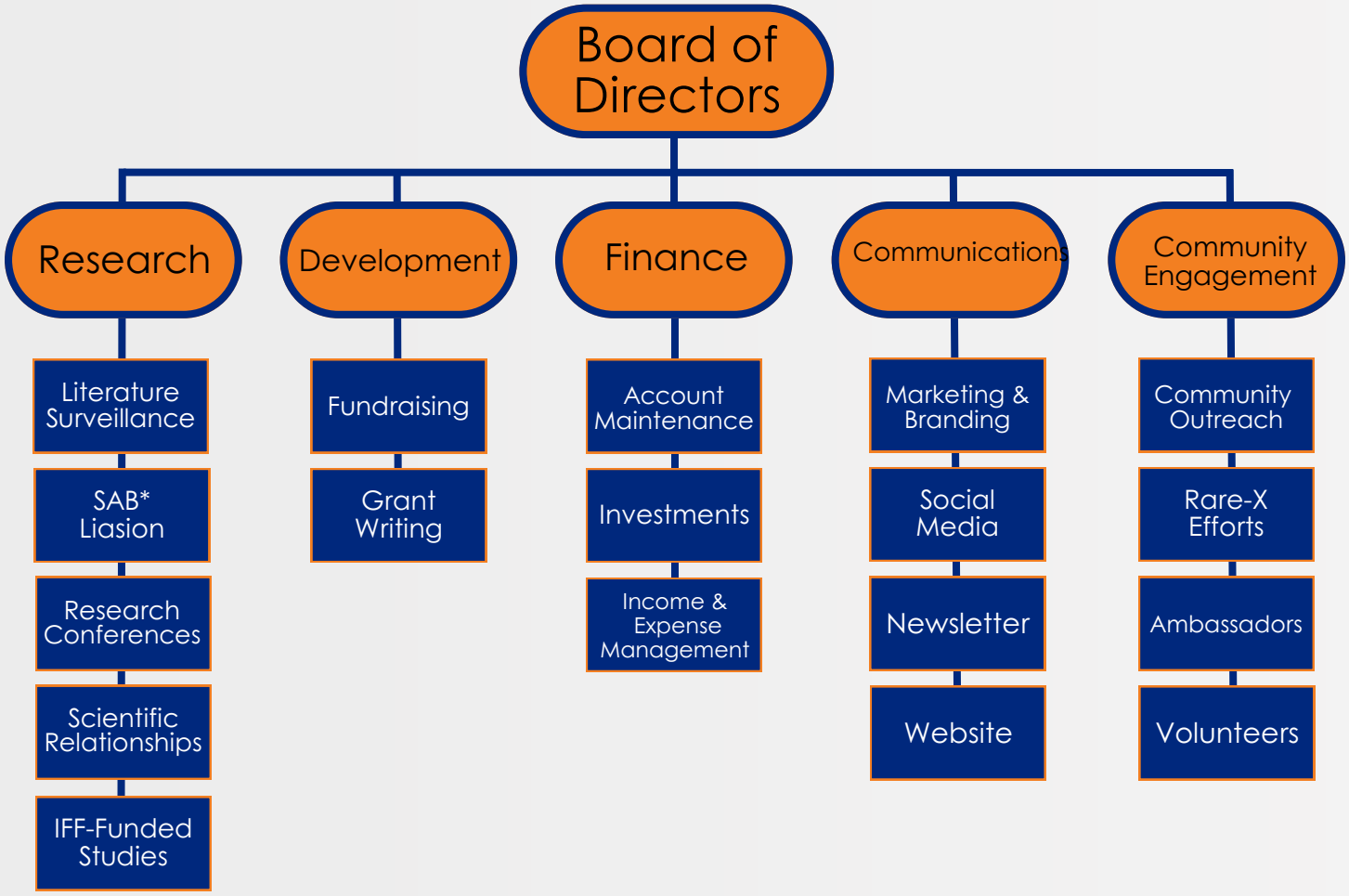
Improve Financial Position

Improving our financial position and community reporting, including diversifying our revenue, finding new grant opportunities, and providing fiscal reports to the community are all crucial for continued sustainability and fiscal stewardship. Improving our financial position also helps to build capacity and expand our programs, services, and resources to the international FOXP1 community

Organizational Chart

While many areas of capacity building were identified, an organizational chart was also developed to help the organization elucidate roles within the organization. The organizational chart is provided below.

Executive Committee
Key Responsibilities



* SAB = scientific advisory board

Tactics & Timeline

In order to appropriately budget time for the strategies we've laid out before you, we've developed the following "tactics and timeline" table. We expect to realistically achieve these tactics with little fluctuation in the timelines listed below.

0-6 Months

- Release request for research proposal
- "Pilot" an in-person, regional meet-up
- Finalize an awareness day
- Finalize organizational budget
- Develop communications plan
- Host a research conference
- Fund phase one research grants
- Develop a welcome packet
- Develop a fundraising calendar
- Engage more volunteers
- Design and offer FOXP1 merchandise / swag

6-12 Months

- Announce research grant recipients
- Develop fundraising plan
- Develop 2025 budget
- Host an open house
- Launch natural history study
- Finalize succession plan
- Volunteer recruitment
- Delegate ambassadors for Zoom chats
- Select a CRM (consumer relationship management) software
- Refresh website

12-24 Months

- Host 2nd FOXP1 family meeting
- Publish results from research
- Host a patient-focused drug development meeting
- Expand industry relationships
- Develop a research plan
- Increase branding
- Transition some volunteers to the board of directors

24-36 Months

- Increase investments
- Increase diversity of membership
- Apply for an ICD-10 code
- Advocate to have FOXP1 gene added to prenatal genetic testing panels
- Natural history study - recruitment continues

Three Year Key Results

Over the next three years, the International FOXP1 Foundation will hold ourselves accountable for the strategy and key measurable goals we've laid out. We will provide annual progress reports to you, our community, to update you on the progress of our strategic objectives.

BY 2027, KEY RESULTS INCLUDE:

Research

- Multiple research grants funded
- Multiple publications from International FOXP1 Foundation-funded research
- Research symposium(a) held, ideally annually
- Natural history study well underway
- Successful recruitment and engagement of families into research studies
- Research plan finalized and implemented with annual reports sent to the community
- Patient-focused drug development meeting held
- ICD-10 code received
- FOXP1 added to prenatal testing panel

Community Building

- Expand international outreach
- Finalize annual FOXP1 awareness date with annual activities developed
- Identify and engage more volunteers
- Increase zoom chats internationally
- Host 1-2 global family conferences in person
- Increase outreach to families through strategic partnerships with medical professionals
- Implement new “buddy” program
- Increase marketing of FOXP1 brand and merchandise
- Engage more families through in-person meetups

Support

- Newly diagnosed outreach ongoing
- Welcome packet developed and in use
- Multiple in-person, regional meet-ups hosted
- Continued Zoom chats led by ambassadors
- Multiple open houses hosted

Information Sharing

- Host 1-2 global family conferences in person
- Develop new printed materials, including information for newly diagnosed
- Distill scientific information for the community in an easy-to-understand way
- Refresh website with updated scientific information
- Increase social media presence to ensure regular scientific communications
- Use wide array of social media platforms

Sustainability & Capacity Building

- Follow approved budget annually
- Develop communications plan
- Develop fundraising plan and calendar
- Increase volunteer pool
- Develop succession plan
- Increase and foster industry relationships
- Position the International FOXP 1 Foundation for investment opportunities
- Manage constituent relationships more effectively

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