



2023 - 2027

Strategic Plan



FANCONI ANEMIA
RESEARCH FUND

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A new chapter for the next generation

We are excited to present the Fanconi Anemia Research Fund's (FARF) strategic plan for 2023-2027. This plan continues the remarkable progress we have made in understanding the genetics of FA and sets the stage for exponential growth in FA cancer research.

Since our founding in 1989, FARF has raised over \$32 million for research, provided support to thousands impacted by FA, pioneered life-saving therapies, and made the ground-breaking discovery that the 23 FA genes we have identified, when working properly, constitute the body's defense against cancer. Building upon these achievements, we are now ready to embark on a reimagined approach to FA cancer research.

Our 2023-2027 strategic plan elevates FA cancer research within a consortium model, multiplying our efforts through collaborations with research centers all over the world. To achieve this, we will enhance our capabilities in research administration, support services, fundraising, and governance.

The aspirations outlined in this plan are ambitious, yet firmly rooted in our legacy of success, compassion, and an unwavering sense of urgency. With your support, we will accelerate progress for individuals affected by FA and FA cancer.

Thank you for your ongoing commitment and generosity as we embrace this new phase.

Sincerely,

Mark Quinlan
Executive Director



This plan sets the stage for exponential growth in FA cancer research, and is firmly rooted in our legacy of success, compassion, and an unwavering sense of urgency.

Vision

We envision a future where we can prevent and treat the primary cause of death and disability in people with FA, enabling them to live full and productive lives.

Mission

To find better treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide.

Values

Leadership

FARF will lead research to develop clinically relevant treatments for individuals with Fanconi anemia.

Cooperation and Collaboration

FARF will coordinate researchers, other funding organizations, private industry, and support groups to work together to improve the lives of people with FA.

Family-Driven

FARF strives to integrate people with FA and their families into the direction and decision-making of the organization.



Adaptability

FARF aspires to be nimble, adapting to the evolving needs of individuals with Fanconi anemia and their families, to scientific discoveries and technology, and to the realities of the changing economy.

Stewardship

FARF strives to use the money entrusted to it to support its mission in a way that will maximize the benefit to individuals with Fanconi anemia (FA) and to their families.

Integrity

FARF will be transparent, honest, ethical, and respectful in all interactions with employees, families, researchers, and the public.

2023-27 Strategic Goals

Focus on Research

GOAL 1: Accelerate FA cancer research and therapeutic approaches through external partnerships

- With partners, develop FA Cancer Consortium resource sharing and governance structure
- Identify novel innovative prevention and therapeutic approaches for FA cancers
- Test novel prevention and therapeutic approaches

Focus on Community

GOAL 2: Accelerate research through increased advocacy, community engagement, and psychosocial support

- Build community advocacy program to advance FA cancer research
- Accelerate research on well-being and develop partnerships to enhance psychosocial support efforts
- Continue to foster the international FA collaborative network to expand community engagement and access to support

Focus on Sustainability & Growth

GOAL 3: Achieve a stable, sustainable development base

- Secure founder-transition funding base
- Stabilize current revenue streams
- Develop sustainable systems for managing revenue streams

GOAL 4: Diversify and expand funding sources

- Expand current revenue sources
- Investigate and establish new revenue streams
- Investigate and pursue external partnerships

GOAL 5: Evolve brand “beyond FA” by connecting FA research impact to cancer community

- Carry out rebranding process and repositioning of FARF as cancer-focused organization
- Create comprehensive marketing and communications plan to align with cancer focus

Focus on People

GOAL 6: Create optimal adaptive environment for people and leadership to contribute

- Create enabling processes and structures to support the strategic plan through anticipated stages of development
- Build and support a working environment that attracts and retains top talent and helps employees advance FARF's work
- Implement diversity, equity, and inclusion (DEI) policy across organizational activities and stakeholder groups



Research

The 2023-2027 strategic plan highlights FARF's commitment to accelerate FA cancer research by focusing on improving early detection, prevention, and treatment. Our goal is to expedite research progress by growing and formalizing the FA cancer research consortium, which fosters interdisciplinary collaborations, engagement with individuals in the FA community, and open data and resource sharing.

We will serve as the primary funder of new research projects within the consortium, establish sustainability and oversight policies, support international data sharing, and empower patient advocates to contribute to clinical research.

The strategic plan aims to achieve positive outcomes by increasing funding for FA cancer research through philanthropic support and strategic partnerships. By investing in research and people, we will foster the innovation necessary to enhance clinical care for FA cancer.



Pictured: internationally renowned FA clinicians Carmem Bonfim (left), Farid Boulad, and Margy MacMillan.

Goal: Accelerate FA cancer research and therapeutic approaches through external partnerships

A. With partners, develop FA Cancer Consortium resource sharing and governance structure

- Maintain FARF program management capabilities and scale as needed
- Develop governance strategy for FA Cancer Consortium
- Leverage external partnerships to build infrastructure for FA cancer international data sharing and biorepository
- Create FA cancer pre-clinical models and support resource sharing infrastructure

B. Identify novel innovative prevention and therapeutic approaches for FA cancers

- Grow FA cancer researcher network with emphasis on recruiting new investigators
- Fund competitive, collaborative, FA cancer research investigator-initiated grants
- Leverage expansion of FA Cancer Consortium through facilitating partnerships with external funding sources

C. Test novel prevention and therapeutic approaches

- Build FARF program management capabilities to support FA Cancer Consortium clinical initiatives
- Create and grow FA clinical network as part of the FA Cancer Consortium
- Leverage clinical and scientific community to develop patient-centered FA cancer research clinical trials
- Develop industry engagement plan and expand partnerships to develop patient-centered FA cancer research clinical trials

Participants in the FA Cancer Consortium





Community

FARF remains committed to providing support services and fostering connection, while enhancing the patient and family's role in research. Recognizing the complexity of patient and family needs, we acknowledge the limitations of our resources. To address this, we are engaging with external partners to broaden psychosocial research and support. This initiative aims to promote and improve wellbeing, while also empowering individuals to participate in FA research.

The strategic plan recognizes the trust placed in us by those impacted by FA and aims to empower them by involving them in decision-making and research design. Adults living with FA (and future generations) seek agency in their cancer journey, and their voices are heard and valued. To this end, the establishment of a formal advocacy program is a part of this strategic plan.

To better meet the diverse needs of the FA community, we are actively working with global patient organizations to empower FA communities and amplify their impact. We will promote self-sustained programs within international FA organizations to ensure this support and advocacy long term.



Pictured: Ana Tabar, adult with FA, leader of the FA Support Group in the Dominican Republic, and voice in Spanish-speaking FA community

Goal: Accelerate research through increased advocacy, community engagement, and psychosocial support

A. Build community advocacy program to advance FA cancer research

- Amplify patient and family perspectives in research activities to enhance trial design and recruit participants
- Develop standardized programming and advocate training for advocacy efforts
- Develop patient and family education materials to enhance disease-relevant knowledge and accelerate clinical trial awareness

B. Accelerate research on well-being and develop partnerships to enhance psychosocial support efforts

- Accelerate patient-directed psychosocial research to support well-being initiatives for people with FA
- Partner with external stakeholders to develop a collaborative psychosocial patient support network and integrated initiatives
- Develop patient and family psychoeducation materials and resource navigation assistance

C. Continue to foster the international FA collaborative network to expand community engagement and access to support

- Foster partnerships with key international patient support organizations
- Promote self-sustained programming among international patient advocacy organizations





Sustainability & Growth

Fundraising is vital to the success of our mission, and the 2023-2027 strategic plan focuses on the stewardship and expansion of fundraising efforts, strategic coordination of branding and messaging, and outreach to current and new stakeholders.

Refreshing our brand to reflect the increased focus on FA cancer holds significant promise for expanding our growth opportunities and establishing a presence beyond the FA and rare disease communities. Furthermore, the strategic integration of the FARF brand, messaging, and communications with the FA Cancer Consortium will enable us to maximize our impact.

Historically, FARF has heavily relied on the founder network and a dedicated yet relatively small group of FA families for fundraising support. However, to achieve our aspirational goals and ensure long-term sustainability, it is essential to transition from founder-driven funding to organizational-driven funding.



Pictured: participants at the annual Coley's Cause Memorial Golf Tournament fundraiser

Goal: Achieve a stable, sustainable development base

A. Secure founder-transition funding base

- Build and implement founder transition plan to perpetuate historically significant funding

B. Stabilize current revenue streams

- Evaluate efficacy and improve systems for peer-to-peer fundraising program, major giving program, recurring giving and employer-match program

C. Develop sustainable systems for managing revenue streams

- Define donor segments and pipeline to better match current and prospective donors with organizational programs and goals
- Update comprehensive stewardship and marketing plan

Goal: Diversify and expand funding

A. Expand current revenue sources

- Cultivate major gifts, peer to peer program, recurring giving

B. Investigate and establish new revenue streams

- Cultivate estate giving, corporate giving, and grants

C. Investigate and pursue external partnerships

- Create network of external FARF supporters in key sectors, including industry and government

Goal: Evolve brand “beyond FA” by connecting FA research impact to cancer community

A. Carry out rebranding process and repositioning of FARF as cancer-focused organization

- Reinvigorate organizational identity with cancer focus, including potential name change, mission revision, visual identity refresh, and updating organizational storytelling and messaging

B. Create comprehensive marketing and communications plan to align with cancer focus

- Engage with marketing company to outline full marketing plan focused on sustaining patient/family and researcher/clinician base, and broadening outreach and donor base



People

The Frohnmyer (founder) legacy encompasses more than just financial support—it embodies drive, intellect, care, compassion, and success. The individuals involved with FARF are propelled by a sense of urgency, matched only by their collective talent and dedication to their shared purpose.

The 2023-2027 Strategic Plan builds upon a solid governance model established in the past, while navigating the new challenges of pivoting to a more explicit focus on FA cancer and the consortium model.

Retaining highly qualified staff and preventing burnout are shared organizational priorities acknowledged by all leadership bodies. The Board of Directors recognizes the importance of establishing a development subcommittee to engage, support, and monitor the ambitious goals for expanding and diversifying funding sources. Additionally, upholding diversity, equity, and inclusion (DEI) is an integral aspect of FARF's guardianship.

Finally, it is crucial to underscore the foundation of trust that the FA community has placed in FARF. People with FA and their families played a central role in the development of this strategic plan, and their involvement will continue to be vital during its implementation.



Goal: Create optimal adaptive environment for people and leadership to contribute

A. Create enabling processes and structures to support the strategic plan through anticipated stages of development

- Adopt ongoing strategic planning process for tracking and responsive decision making
- Integrate new strategic planning metrics with existing financial & research metrics for tracking & reporting
- Create a development subcommittee of the board
- Integrate goals, activities and communications between key board groups and subcommittees, including establishing board liaison positions for key strategic initiatives

B. Build and support a working environment that attracts and retains top talent and helps employees advance FARF's work

- Develop an objective 360 process for evaluating organizational satisfaction with employees, board/groups & key collaborators
- Ensure organizational policies so that compensation, benefits and employee support meet industry standards

C. Implement diversity, equity, and inclusion (DEI) policy across organizational activities and stakeholder groups

- Incorporate principles of diversity, equity and inclusion into leadership and staff recruitment, and in the development of research and family support programs
- Develop ongoing evaluation process to measure DEI efforts and outcomes



Members of the FA Adult Council at the 2023 Annual Leadership Meeting. Top, from left: Fatma Isaak, Dexter Sherrell, David Rodwell, Will Bloxom, Jasmine Bennetsen. Bottom, from left: Michelle Watkins, Matthew Pearl, Andie Kalembo

Supporting the Vision: Strategic Plan Resources

To accomplish what is outlined in this plan, the Fanconi Anemia Research Fund has set a target for its direct philanthropic initiatives to grow 43% by the end of 2027, with an average rate of 7.5% per year. These estimates do not include projections for potential increased FACC revenue contributed by external consortium collaborators.

In our projection, about 80% of annual revenue will come from existing streams, while 20% of annual funding will come from new expanded and diversified sources (Figure 1).

The operating budget, which was \$3.5 million in 2022, is expected to reach \$5 million by 2027. The organization's most directly impacted areas of growth are the FA Cancer Consortium (FACC), and an investment in development and marketing.

Throughout this budget growth, FARF aims to maintain a well-balanced investment across research, development of the FACC, community and support services, and development and administration (Figure 2).

FIGURE 1: Projected revenue growth

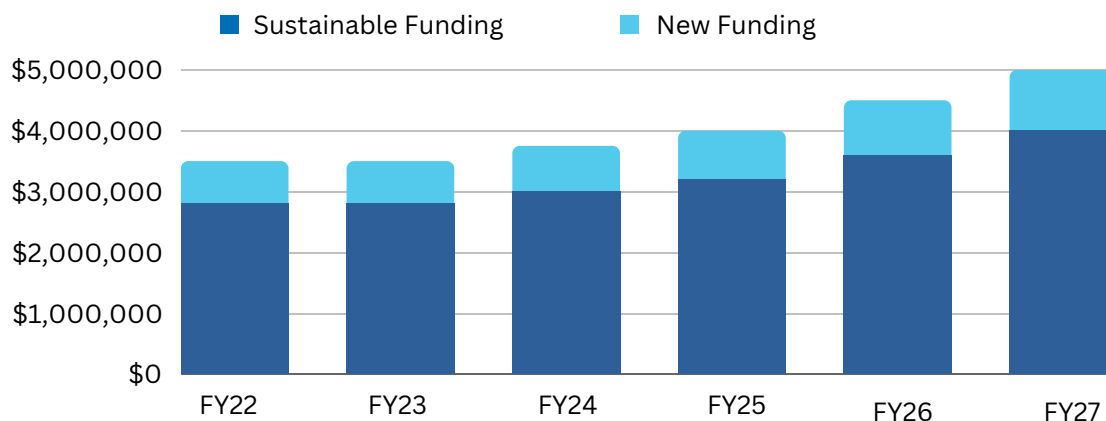
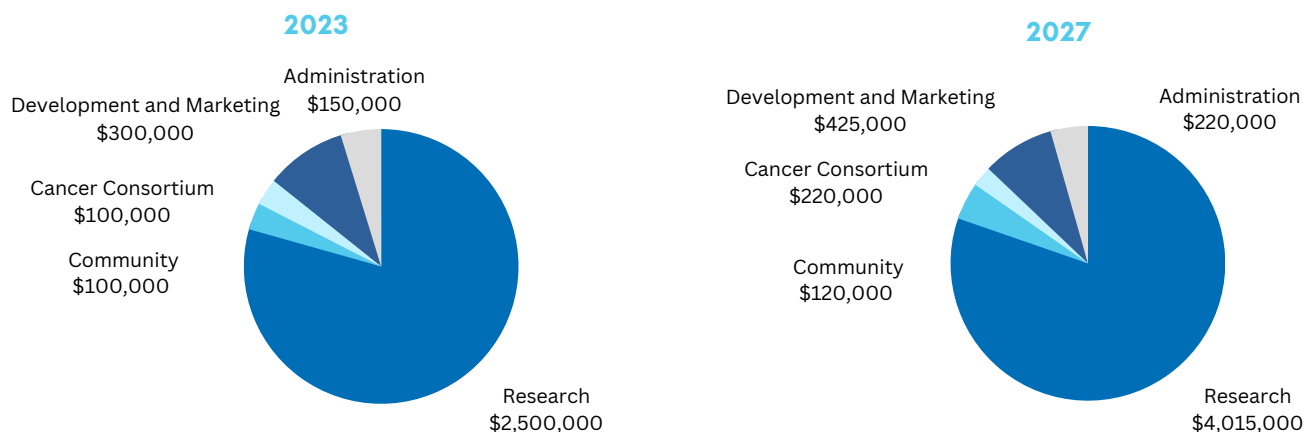


FIGURE 2: Allocation of resources



Thank you

We wish to express our appreciation for your unyielding support and relentless dedication to the cause. We reaffirm our shared commitment to driving progress and transforming the lives of those impacted by Fanconi anemia.

Research

Expand cancer research and therapies through external partnerships

- Develop Consortium
- Identify therapies
- Test therapies

Community

Accelerate research through community advocacy and engagement

- Develop advocacy program
- Fund psychosocial research
- Support community

Sustainability & Growth

Diversify and expand funding

- Stabilize revenue
- Expand revenue
- Refresh branding

People

Create optimal adaptive environment for people and leadership to contribute

- Measure progress
- Attract and retain talent
- Incorporate DEI principles

Our vision is a future where we can prevent and treat the primary cause of death and disability in people with FA, enabling them to live full and productive lives. This plan accelerates our vision.