

ConnectMyVariant

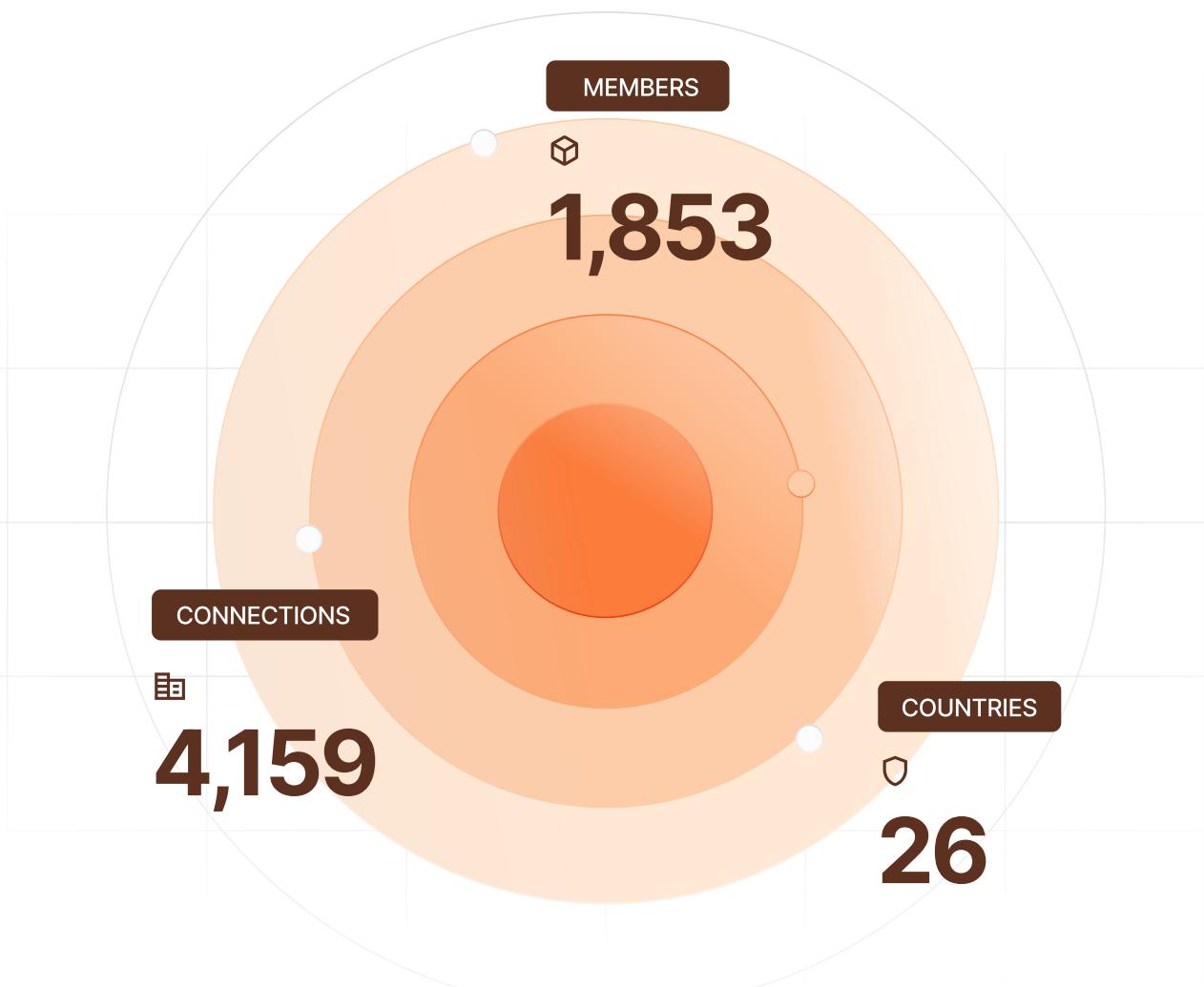


# FY 2025 Impact Report

July 1, 2024 - June 30, 2025

ConnectMyVariant is a growing community that helps families find one another, share information, and take action to prevent hereditary disease.

**Together we are accelerating access to *testing, counseling, and lifesaving care.***



# How ConnectMyVariant Creates *Impact*?

Our model connects families, accelerates testing, and saves lives through early intervention

## 1. Connect

- ↗ Families with genetic variants find each other through our platform

## 3. Act

- ⌚ Relatives get tested earlier and access preventive care

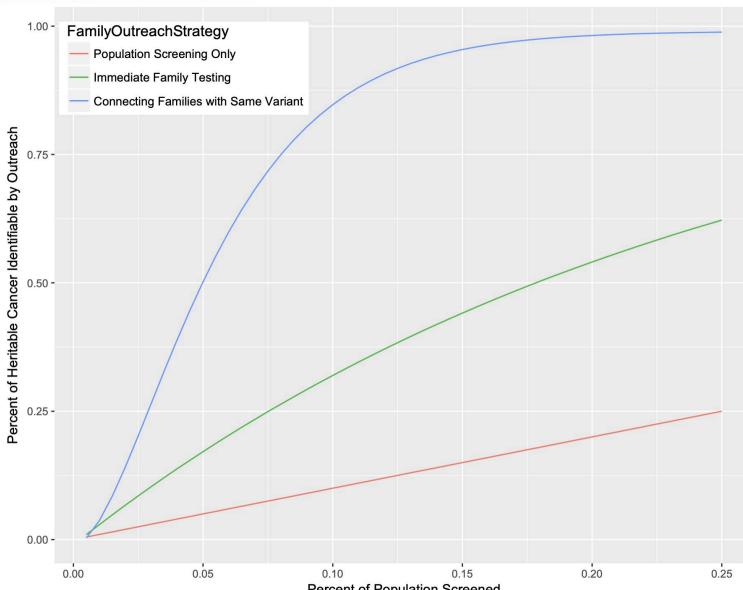
## 2. Share

- 👤 Members exchange information and support with genetic counselor guidance

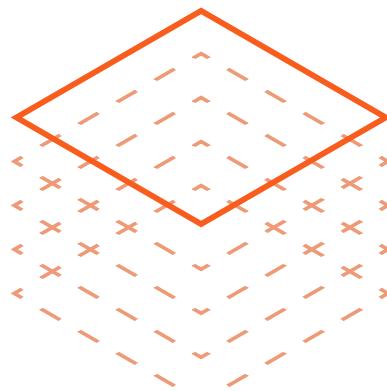
## 4. Prevent

- 👉 Earlier detection and intervention prevents hereditary disease

## Our Solution in Action



Every connection creates a ripple effect of prevention across families and generations



## Why This Matters

• **160 M**

people have inherited disease risk

• **90%**

of hereditary disease can be prevented or slowed

• **<2%**

know about their risk

# Letter from our *Board President*

ConnectMyVariant has grown from a few people into a community dedicated to ending hereditary disease. Our focus on family-to-family outreach, genetic counseling support, and free genealogy assistance to help individual families grow and come together into communities that help each other is unique.

We now bring together nearly two thousand members across the United States and around the world. Every new connection helps another person understand their risk, get genetic testing, and reach preventive care sooner.

We have struggled to find continuous funding. I'll be honest: healthcare systems and insurers are not set up to invest in prevention. We will continue to engage with healthcare systems, but it is becoming clear that our main focus will need to stay on the families that we serve. Each donation that we have received has been leveraged to enable hundreds of hours of volunteer effort.



Brain Shirts

“ Your participation helps turn *knowledge* into action for families everywhere. ”

We are grateful for the time, energy, and expertise that volunteer, healthcare partners, and most of all, you contribute each day.

## Board Priorities for 2026



Expand enrollment in underserved communities



Scale navigator program



Launch multilingual resources

# Voices from Our *Community*

Real families, real impact, real prevention



Fan

## Fan's Story:

“Please do not assume that you have escaped inheriting a gene mutation unless testing confirms it. I believed that I was past the age of risk. Had I been tested, I could have opted for a double mastectomy. I could have avoided the ravages of chemotherapy and many moments of fear and terror. Thanks to genealogy and genetic testing, several of my family members have been able to avoid these experiences.”

### Impact:

- 29 relatives identified and contacted
- Variant traced back 5 generations

## Joanne's Story

“I worked with ConnectMyVariant volunteer genealogist Emma to find distant relatives who might share my MLH1 variant. Since there wasn’t paper documentation on births and deaths in my family, we turned to DNA testing. My Ancestry results matched me with potential family members who had also taken the test. Emma used computer software to identify people from my father’s side, and I sent messages to them through the Ancestry website. I asked about their grandparents and parents, and Emma pieced the connections together into our family tree.”

### Impact:

- 3 children tested positive
- 2 additional relatives identified
- Family tree expanded across 3–4 generations



Joanne

“The navigators made everything clear. I went from terrified to empowered.”

– Member, PALB2 variant

“My kids now have a roadmap for prevention we never had before.”

– Member, ATM variant

“Finding others with my rare variant gave me hope and practical guidance.”

– Member, Lynch Syndrome

# *Impact at a Glance*

## Year-Over-Year Growth

**1,260**

People signed up

Start of Year

**+47%**

Growth



**1,853**

People signed up

End of Year

## Key Metrics

**4,159**

Family Connections Made

**23**

variant groups with Variant Champions

**250**

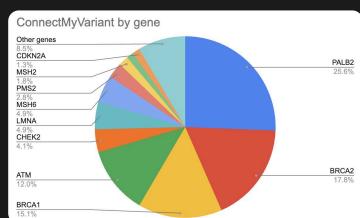
Genetic Counselors Engaged

## Geographic Reach



Present in 46 US states with concentrated growth in underserved regions

## Variant Distribution



Supporting families across 50+ different disease-causing genes

Member Distribution Across  
**26 Countries**

# Programs and Strategic *Progress*

Responsible growth funding sustainable impact

## Ashley Doyle Scholarship Launched

We established the Ashley Doyle Scholarship Fund to honor Ashley Blair Doyle, a fearless advocate for hereditary cancer prevention and a champion of family outreach.

The scholarship supports volunteers assisting with hereditary cancer outreach, including students and early-career genetic counselors.

### 2025 Inaugural Recipient

**Katy Meta** – Pittsburgh, Pennsylvania

“ Attending the 43rd annual NSGC conference reinforced my goal of becoming a genetic counselor and deepened my focus on cancer prevention.

”

## Strategic Achievements

### 🌐 Scaling Services

- Volunteer training program launched
- Navigator network expanded
- Alliance for Genomic Justice campaign
- National conference presence

### 🤝 B2B Partnerships

#### Goal: 6 entities

- Vanderbilt (3-year)
- RUNX1 Foundation
- Roswell Park
- Fred Hutch

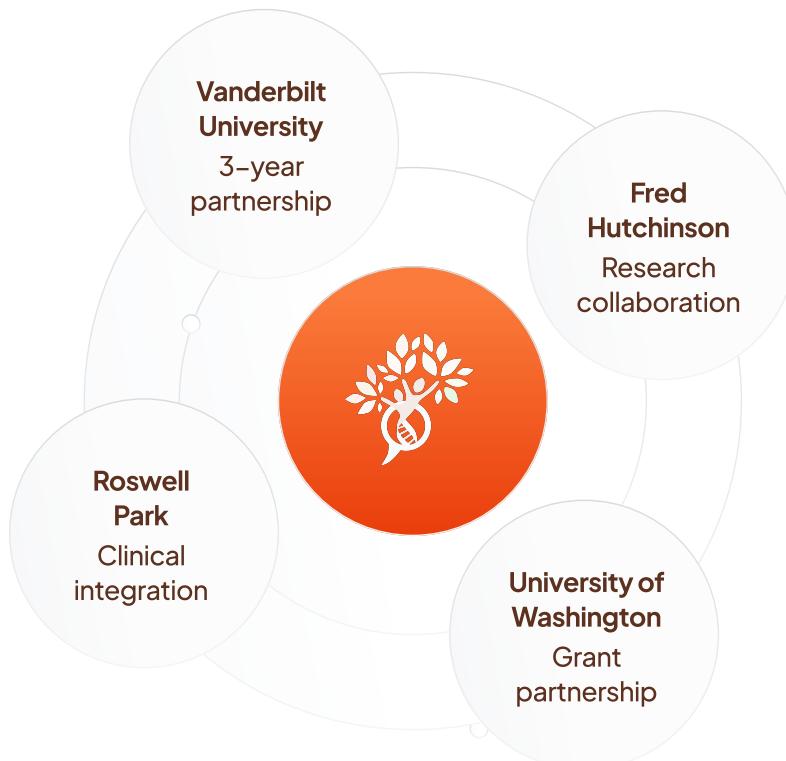
### 📍 Community Presence

- Roots Fest
- NSGC Annual Meeting
- CGA-IGC collaboration
- Regional workshops

# Building a *Network* for Change

Our impact multiplies through strategic partnerships and collaborations

## Healthcare Partners



## Community Organizations

### Alliance for Genomic Justice

Collaborative outreach campaign reaching underserved communities

### Research Consortiums

ClinGen MM VCEP, RUNX1 Foundation

#### Collaborative Outcomes

- Variant classification improvements
- Family registry development

## Supporting Organizations

BYU-Center for Family History and Genealogy

MyFaultyGene

Inherited Cancers Australia

Colorado Lynch Syndrome Symposium

FORCE (Facing Our Risk of Cancer Empowered)

LMNA foundation

Ambry Genetics

Family Gene Share

Genetic Support Foundation

Alliance for Genomic Justice

# Financial Stewardship

Responsible growth funding sustainable impact

**\$199,418**

Total Revenue

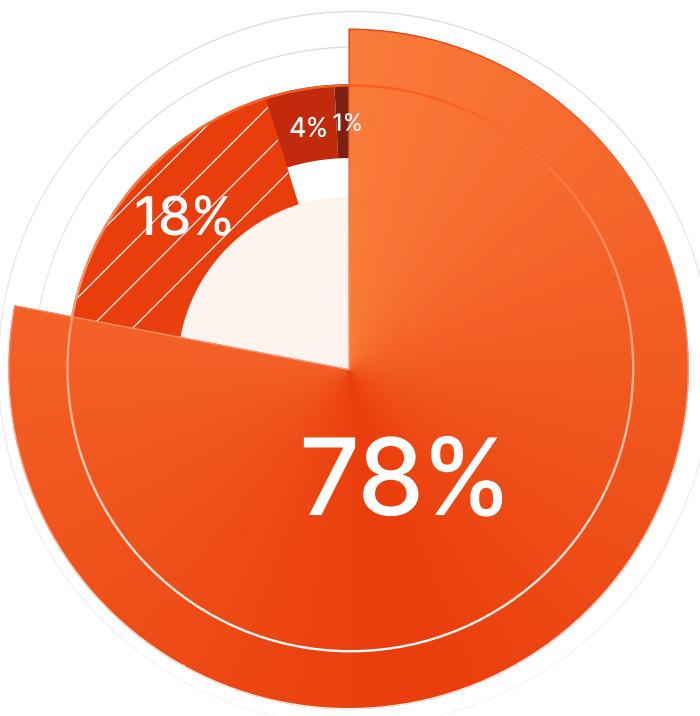
**47%**

YoY Growth

**\$118,735**

Operating Expenses

## Revenue Sources



Grants: \$155,416 Contributions: \$35,763 Service Revenue: \$7,450  
Other: \$789

## Financial Highlights

Grant that has been the major source of revenue ending this year.

Positive net operating income ensures sustainability

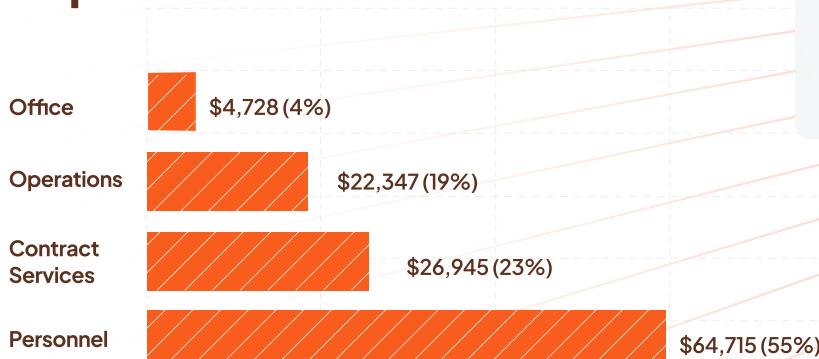
78% of expenses directly support programs and services

Diversifying revenue with B2B subscriptions for long-term stability

Current Health System subscriptions

- Roswell Park Comprehensive Cancer Center
- Ascension St Vincent
- Endeavour Health, Neaman Center for Personalized Medicine
- Vanderbilt Ingram Cancer Center

## Expense Allocation



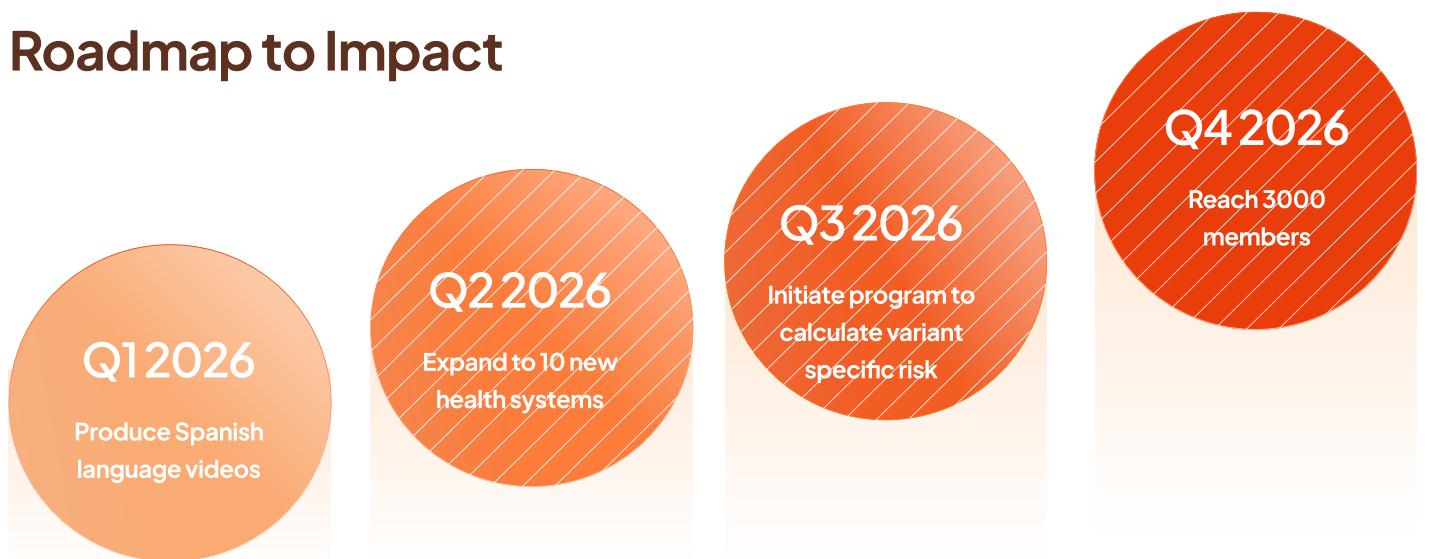
2024

# Vision for Tomorrow

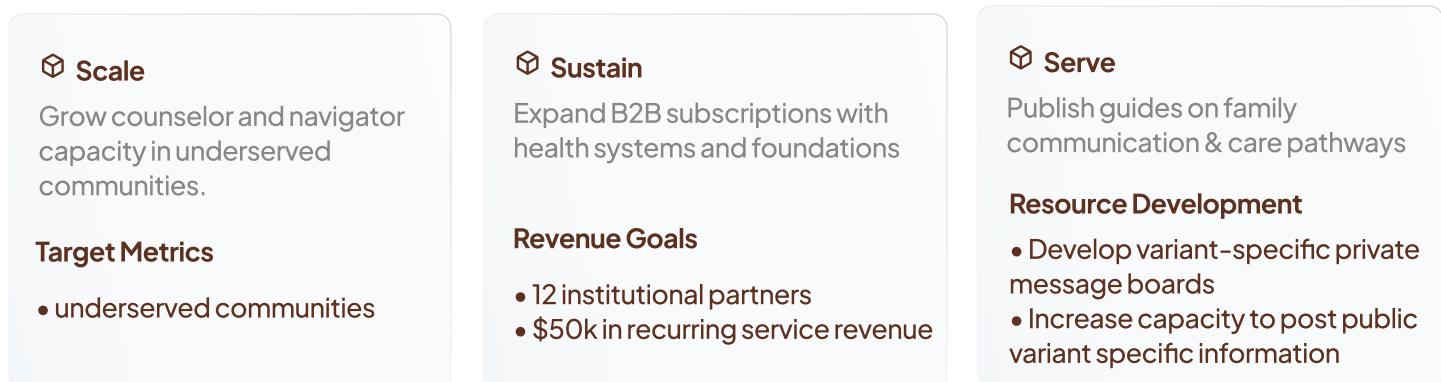
## Our 2026 Goals

“Expanding our reach, deepening our impact, and building sustainable systems for prevention at scale”

## Roadmap to Impact



## Strategic Priorities



## Join Us in Ending Hereditary Disease

Every action you take helps another family access lifesaving prevention

[Become a Volunteer](#)

[Support the Scholarship](#)

[Share Your Story](#)

[Partner With Us](#)

# Thank You to Our *Community*

“

Thank you to our *members, volunteers, partners, and supporters* for another year of progress toward ending hereditary disease.

”

## Board of Directors

Brian Shirts . Carole Eldridge . Chandler Lewis . Wenora Johnson  
. Leann Seddon . Betty Johnson . Emily Malouf

## Executive Advisory Board, Medical and Science Advisory Board, Patient and Family Member Advisory Committee

Amber Abram . Beth Devine, Evelyn Fang . Michelle Springer . Susan Weiss Liebman . Nora Henrickson . Irene Newsham . Alice Childs . Angela Eden . Dina Margulies . Kathy Baker . Peter Marusca . Joanne Harrington . Fran Barrett . Maddie Williamson

## Special Volunteers

**Caitlin Shirts** – Newsletter  
**Mark Hicks** – Illustrations  
**KC Kent** – Sales Support

**Martha Kaiser** – Biostatistics  
**Estrella Ulloa** – Hispanic Outreach

*A very special  
thank you to*

**Our Family Outreach Navigator and  
Variant Champion Volunteers!**



# *Stay Connected* ConnectMyVariant

✉ [info@connectmyvariant.org](mailto:info@connectmyvariant.org)

🌐 [connectmyvariant.org](http://connectmyvariant.org)

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