THREE-YEAR STRATEGIC PLAN · 2026–2028

Built with the pheochromocytoma and paraganglioma community.

A plan built by and for the people living with pheochromocytoma and paraganglioma (PPGL) — grounded in real evidence, guided by what this community told us matters, and made to last.

8,038
patients, caregivers & clinicians

19
Centers of Excellence (COE), six continents

5
priority areas, one purpose

Prepared by JoBeth McCarthy, DHSc, MPH, CPH · Executive Director · June 2026

BUILT BY AND FOR THE COMMUNITY

This plan began with listening.

Beginning in January 2026, we surveyed our Board, held key informant interviews and listening sessions, and then issued a draft plan — gathering feedback from across the community, including patients, caregivers, researchers, clinicians, and advocates. Now we are finalizing the plan they helped shape. Patients and caregivers are the heart of every priority; the priorities are ordered by what we have to build first, not by who matters most.

HOW WE LISTENED

01 · Listen	**Listening sessions.** Patients, caregivers, providers, advocates, and volunteers shared what matters most.
02 · Interview	**Key informant interviews.** In-depth conversations with the Board, advisory boards, clinicians, researchers, and partners.
03 · Survey	**Board survey.** The Board Strategic Alignment Survey turned leadership perspectives into a clear, shared direction.
04 · Refine	**Draft, feedback, finalize.** We issued a draft plan, gathered feedback from the whole community, and are now finalizing it.

WHAT THE COMMUNITY AFFIRMED

The same priorities came up again and again — they are the foundation of this plan.

- → Patient- and caregiver-centered approaches
- → Patient- and caregiver-centered research
- → Strengthening our global reach
- → Patient-centered registry & data infrastructure
- → Industry collaboration

FROM OUR LEADERSHIP

Why we wrote this plan

When I look at our community — more than eight thousand people living with pheo or para and their caregivers, and nineteen COEs across six continents — I see a field that a small, dedicated team chose to build before anyone else recognized it. This plan makes that identity official: resourcing it, governing it, and sharing ownership of it across the global PPGL community.

It was shaped by your voices. You will notice this plan leads with people, not programs — everything else exists to reach you sooner and serve you better, wherever you live. The scientific moment has arrived; what remains is the discipline to follow through, and to measure progress honestly rather than optimistically.

This plan does not ask the Pheo Para Alliance (PPA) to become a different organization. It asks us to become a more capable version of what we already are — the connective tissue of the global PPGL ecosystem, accountable to the people and families at its center. Thank you for being part of it.

JoBeth McCarthy, DHSc, MPH, CPH
Executive Director, Pheo Para Alliance

STATEMENT FROM THE CHAIR OF THE BOARD

"On behalf of the Board of Directors, thank you for the trust you place in the Pheo Para Alliance. We listened to this community at every step — and validated this plan through the 2026 Strategic Alignment Survey. We are committed to governing it with the same rigor we ask of every goal within it, sharing ownership of the work, and holding ourselves accountable to the people and families at its center."

Betsy Herold
Chair, Board of Directors

A SPECIAL ACKNOWLEDGEMENT

With profound gratitude to **Allen Wilson**, **Dr. Karel Pacak, MD, PhD, DSc**, and **Dr. Shonna Snyder, PhD** — for their unwavering support, exceptional consultation, steady guidance, and visionary leadership in helping to create a robust and sustainable future for the Pheo Para Alliance.

ADVISORY LEADERSHIP · ONE TABLE

The clinicians, researchers, and advocates who guide this work.

Our advisory boards and committees bring clinical, scientific, and lived expertise to every priority — keeping this plan grounded, credible, and accountable to the community.

Dr. Karel Pacak, MD, PhD, DSc
Chair, Medical Advisory Board
"This plan holds care to the evidence — so that patients, wherever they are, benefit from the best of what the field knows."

Dr. Shonna Snyder, PhD
Chair, Research & Registry Advisory Board
"A registry turns individual stories into the evidence that moves a field — built with rigor, and with reach into communities too often missed."

Denise Samocki
Chair, Patient Engagement Committee
"People living with pheo or para and caregivers didn't just inform this plan — we are its purpose, at the center of every decision."

Patient & Caregiver Advisors
People living with pheo or para and their caregivers
Patients and caregivers sit at the advisory table — their lived experience guides every priority and every decision in this plan.

WHY THIS PLAN, WHY NOW

The science is moving. The question is who shapes what happens next.

PPGL is rare, genetically complex, and historically under-served. We are the only global nonprofit dedicated exclusively to it — and the connective tissue of a field that is accelerating fast.

8,038
in our community

19
Centers of Excellence

49%
misdiagnosis rate · 29-mo delay

~35%
hereditary — find one, find a family

OUR THEORY OF CHANGE

Lives get better when people are found sooner, clinicians caring for them are better informed, and researchers have the data they need. These four pillars are mutually reinforcing — a registry improves identification; better identification attracts partners; that revenue funds provider education; education improves the referral pathways that populate the registry.

01 · Identify
Finding every person
Earlier diagnosis and faster access to expert care.

02 · Inform
Provider engagement
Engage community providers and support referral and multidisciplinary, coordinated care with COEs — while expanding the COE network.

03 · Discover
Research infrastructure
A data platform that powers clinical trials, real-world evidence (RWE), and partnerships.

04 · Sustain
Funding diversification
Resilient income that sustains all of the above.

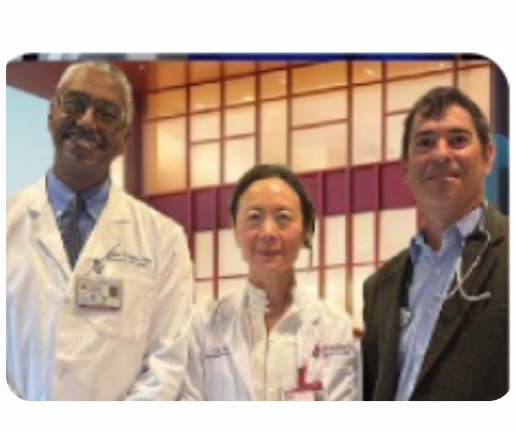
FOR EVERYONE, EVERYWHERE

A global community — met where they are, in their language.

PPA is a global organization, and this plan is for every person and family affected by PPGL — across countries, communities, and circumstances. Equity is not a separate initiative; it is built into every SMARTIE (specific, measurable, achievable, relevant, time-bound, inclusive, and equitable) goal. We design services that meet people where they are, at the right moment, with a culturally and linguistically appropriate approach — which adds to the whole community and takes nothing from those already served. The evidence is consistent: genetic testing for PPGL varies sharply by insurance and age, specialized genetic services remain scarce across much of the world, and Black patients have less access to cancer genetic care.[1–4] And because up to 35% of PPGL is hereditary, finding one person who was missed can protect an entire family.[5,6]

People living with pheo or para

Caregivers



Clinicians

Researchers

Advocates

- → **Care in more languages**
  Patient materials in Spanish and French, with more languages assessed by community need.
- → **Finding people sooner**
  Provider education that closes the 49% misdiagnosis gap and the 29-month delay.
- → **Reaching beyond major centers**
  Outreach to rural, non-academic, and underinsured patients outside COE geographies.
- → **Data that surfaces gaps**
  Registry intake captures demographics and social determinants to reveal and close disparities.

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WHERE WE FOCUS

Five priority areas, sequenced by what we build first.

Each priority area is a cluster of measurable SMARTIE goals. The pages that follow set out the goals and three-year targets behind each.

1 Patient & caregiver support
PEOPLE · CAREGIVERS
Deepen peer programs and care resources, and build self-service infrastructure that scales efficiently as we grow.

2 Clinical network & provider reach
CLINICIANS
Expand the COE network and build a Tier 2 community provider education program that closes the misdiagnosis gap.

3 Research & data infrastructure
RESEARCHERS · PEOPLE
Advance an institutional review board (IRB)–approved patient registry and RWE platform that powers trials and partnerships.

4 Funding diversification & partnerships
ADVOCATES · PARTNERS
Secure a multi-source revenue base so no single partner, grant, or donor carries the mission alone.

5 Governance, capacity & organizational health
BOARD · STAFF · OPERATIONS
Right-size staffing, board, and operations so every other priority can be delivered — the organizational health this plan depends on.

THE GOALS & OBJECTIVES

01 Patient & caregiver support

GOAL 1.1
Digital patient support hub
Registry-linked resources, care kits, peer scheduling, and trial awareness — mobile-first, with Spanish-language support.

2026	2027	2028
Design	1,000+	2,500+

GOAL 1.2
Community-powered fundraising
A self-serve, peer-led playbook of low-barrier events, built on a proven $7K volunteer-run model — unrestricted income not tied to any single partner.

2026	2027	2028
$15K+	$35K+	$50K+

02 Clinical network & provider reach

GOAL 2.1
Tier 2 provider education
Webinars, continuing medical education (CME), and the launch of a COE–community provider eConsult referral pathway for community clinicians — closing the 49% misdiagnosis gap and the 29-month delay.

2026	2027	2028
Pilot	500+	1,000+

GOAL 2.2
Grow the network, globally
Expand our community provider network and grow the COE network globally — adding four COE sites by 2028, including international and Veterans Affairs (VA) sites.

2026	2027	2028
19	20+	22+

03 Research & data infrastructure

GOAL 3.1
PPA Global Registry
An IRB-approved registry with natural history, on the National Organization for Rare Disorders (NORD) IAMRARE platform — $25K secured, contract signed, Registry Advisory Board seated, and the data dictionary being established.

2026	2027	2028
IRB filed	200+	500+

GOAL 3.2
Patient-centered research
Leverage the registry for patient-reported outcomes and natural-history data, and provide research-ready data to launch patient-centered studies and RWE.

2026	2027	2028
Framework	First dataset	RWE published

04 Funding diversification & partnerships

GOAL 4.1
Grow pharma & industry sponsorship
Advance and renew partnerships that fund programs — a sustained, growing program-funding stream.

2026	2027	2028
Established	Growing	Diversified

GOAL 4.2
Four-stream revenue base
Pharma, community, individual & institutional sources — no single stream >50%, plus a 12-month operating reserve.

2026	2027	2028
Mapped	4 streams	<50% each

05 Governance, capacity & organizational health

GOAL 5.1
Refocus the Executive Director role
Move fulfillment, logistics, and bookkeeping off the Executive Director — to staff and outsourced services — so leadership time goes to partnerships, fundraising, and strategy.

2026	2027	2028
Task transfer	ED protected	Ops role added

GOAL 5.2
Board composition & engagement
Recruit 2–3 members who fill expertise gaps, formalize board role expectations, and launch an annual board self-assessment.

2026	2027	2028
Matrix · +1	2–3 added	Reassessed

MID-YEAR SCORECARD · JUNE 2026

Where we are, halfway through the year.

Reviewed at every board meeting and reported in our annual report. The status column reflects our position as of June 2026; targets grow each year as the infrastructure comes online.

MEASURE	STATUS · MID-2026	2027 TARGET	2028 TARGET
Pharma / industry partnerships	● 4 active partnerships	Growing	Diversified
Community fundraising revenue	● $15K+ underway	$35K+	$50K+
Provider touchpoints (non-COE)	● 200	500+	1,000+
COE sites globally	● 19 (+9 in pipeline)	20+	22+
Registry patients enrolled	● Contract signed · IRB filing	200+	500+
Scan of Pheo Para Patient Experiences (SCOPPE) survey respondents	● 200+ (SCOPPE 2.0)	v2.0 published	v3.0 fielded
Digital hub active users	● In design	1,000+	2,500+
Community email subscribers	● 8,500+	9,500+	11,000+
Social media reach (combined)	● 10,000+	12,000+	15,000+
Board members with documented roles	● 100%	100%	100%

● COMPLETE / ON TRACK ● IN PROGRESS

WITH GRATITUDE TO OUR VOLUNTEERS

None of this happens without you.

Behind every priority is a volunteer who makes it real — chairing committees, facilitating groups, packing kits, and rallying the community. This plan depends on them, and we are grateful for every one.

Newly diagnosed care kits
Volunteers who curate, assemble, and ship the kits that reach people at one of the hardest moments.

Patient & caregiver support groups
Facilitators who hold the meetings where no one has to face this alone.

JP Ultra Run, Hike & Heart Campaign
The Planning Committee that turns miles and heart into vital community fundraising.

Scientific Forum Planning Committees
Volunteers who convene the researchers and clinicians whose collaboration moves the field forward.

Medical Advisory Board
Clinicians who volunteer their expertise to keep care grounded in the best of what the field knows.

PPGL Awareness Week
Those who chair, plan, and execute a full week of programming that brings the disease into the light.

Finance Committee
Members who steward the resources and oversight that keep the mission sustainable.

Gala Committee
Those who bring the community together to celebrate the mission and sustain the work.

Board of Directors
Volunteer directors who govern the mission with rigor and hold this plan accountable to the people and families at its center.

Research Advisory Board
Researchers who volunteer their guidance so evidence reaches the patients who are waiting.

TO EVERY VOLUNTEER

You give your time, your energy, and your heart. You are the Pheo Para Alliance — thank you.

THE OPPORTUNITY IN FRONT OF US

No one should face this rare disease without information, expert care, community, and hope.

PPGL research is accelerating: clinical trials are expanding and, for the first time, an approved targeted therapy is reaching some patients. This plan is how PPA helps shape what happens next — which people reach treatment, which providers learn to recognize the disease, and which researchers have the data they need. And it only works with you in it.

BE PART OF THE PLAN

- → Sign up for information about the PPA Global Registry
- → Host a community fundraiser
- → Join a peer support or caregiver group
- → Refer a Center of Excellence near you

→ **Donate** — give your time or make a gift to sustain the mission.

Together, we shape what's next.

pheopara.org · info@pheopara.org · @pheopara

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