

Primary Aldosteronism Foundation

2022 Annual Report



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Letter from the Co-Founders

Dear Friends of the Primary Aldosteronism Foundation,

After joining an online patient support group, the Co-Founders and I realized that, along with many others, we had been undiagnosed and untreated for years, if not decades. Wondering whether a patient initiative might be helpful, we contacted the top-50 clinical researchers listed on Expertscape.com, and received a unanimous response: “yes, it was needed yesterday.” The Primary Aldosteronism Foundation was incorporated shortly thereafter, in September 2019.

We pooled our experience in healthcare, research, business management, and information technology; and committed to developing the organization, starting with establishing its mission: *“advancing standards of care for affected patients through proper diagnosis and treatment, actionable research and inclusive collaboration.”*

We soon became cognizant of the systemic nature of unmet medical needs and realized that a cascade of system failures prevents diagnosis and treatment for 95% of patients.

Building on this assessment, on June 29, 2022, we placed a *Call to Action to Diagnose and Treat Primary Aldosteronism*. The call resulted in the creation of a Stakeholders’ Alliance comprising 34 representatives of medical societies, academic and research institutions, public health organizations, and the private industry.

A *blueprint outlining collaborative interventions* has since been established in support of our programs to:

- Develop machine learning models to find affected patients,
- Increase diagnostic and treatment capacity across US medical centers,
- Investigate the causes of clinical and therapeutic inertia,
- Anchor community of practice and standardization of care in a physician portal,
- Broaden patient support, and
- Strengthen advocacy to influence policies and the prioritization of primary aldosteronism as a major public health issue.

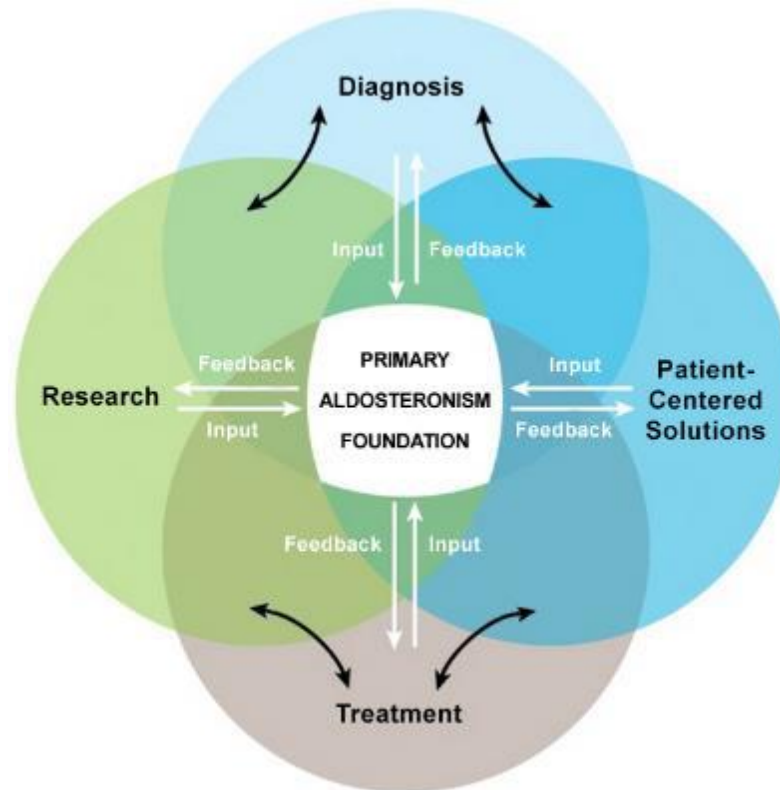
Although worse than most, the patterns of neglect of primary aldosteronism are not unique. We are tremendously grateful for the mentorship of organizations that have paved the way for improved quality of care (i.e., the Family Heart Foundation, T1D Exchange). We are also very thankful for the trust of corporate and individual donors who are supporting us in our start-up phase.

The Primary Aldosteronism Foundation would not exist, and the work we do would not be possible, without you!

Mike McGowan
Marianne Leenaerts
Rene Moreno
Debbie Kelly
Tanya Hanner
Co-Founders and Co-Directors

Who We Are

The Primary Aldosteronism Foundation is a 501 (c) (3) public charity committed to advancing standards of care for affected patients through proper diagnosis and treatment, actionable research, and inclusive collaboration. To achieve this mission, the organization focuses on areas at the intersection of research, diagnosis, treatment, and patient-centered solutions.



In its *advocacy role*, the Foundation acts as the voice of patients to:

- Raise primary aldosteronism to the top of the public health agenda,
- Help identify patients with unmet medical needs, and
- Foster the inclusion of patients' lived experience in research and policies.

In its *catalyst role*, the Foundation promotes accelerated research through funding proportional to the number of affected patients to fill the knowledge gap with regard to aldosterone and the pathogenesis of primary aldosteronism, and to find effective ways of diagnosing and treating the disease at scale.

In its *knowledge translation role*, the Foundation's objectives include:

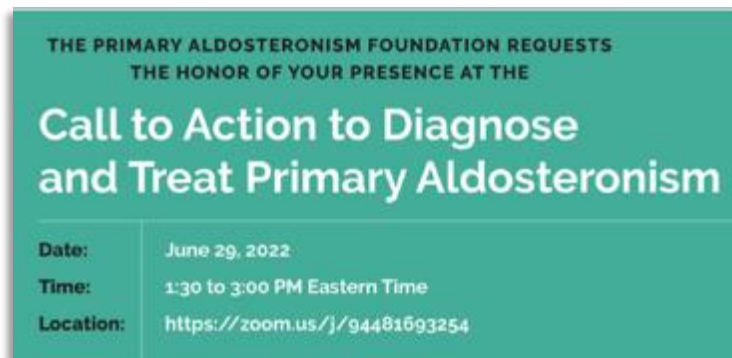
- Promoting the implementation of care models proven successful for diseases with issues similar to those affecting primary aldosteronism;
- Improving quality of care through communities of practice and knowledge translation;
- Fostering collaborative work and disseminating actionable information to patients and healthcare professionals.

Our Call to Action

During the first couple of years following its incorporation, the Primary Aldosteronism Foundation focused on identifying the *critical factors* contributing to unmet medical needs and held consultations with *key stakeholders* responsible for diagnosis and treatment (e.g., ASN, ACC, Endocrine Society, AAFP, ACP, AHA, CDC, FDA, NIH).

All stakeholders acknowledged the limitations of the healthcare system to address patients' medical needs.

They all committed to participating in the *first roundtable* organized to create the paradigm shift to reframe hypertension in the context of hyperaldosteronism.



The Call to Action convened *34 high-profile executives* from the above-mentioned stakeholders' groups.

Held online, the event included plenary and breakout group sessions, and was moderated by a professional facilitator.

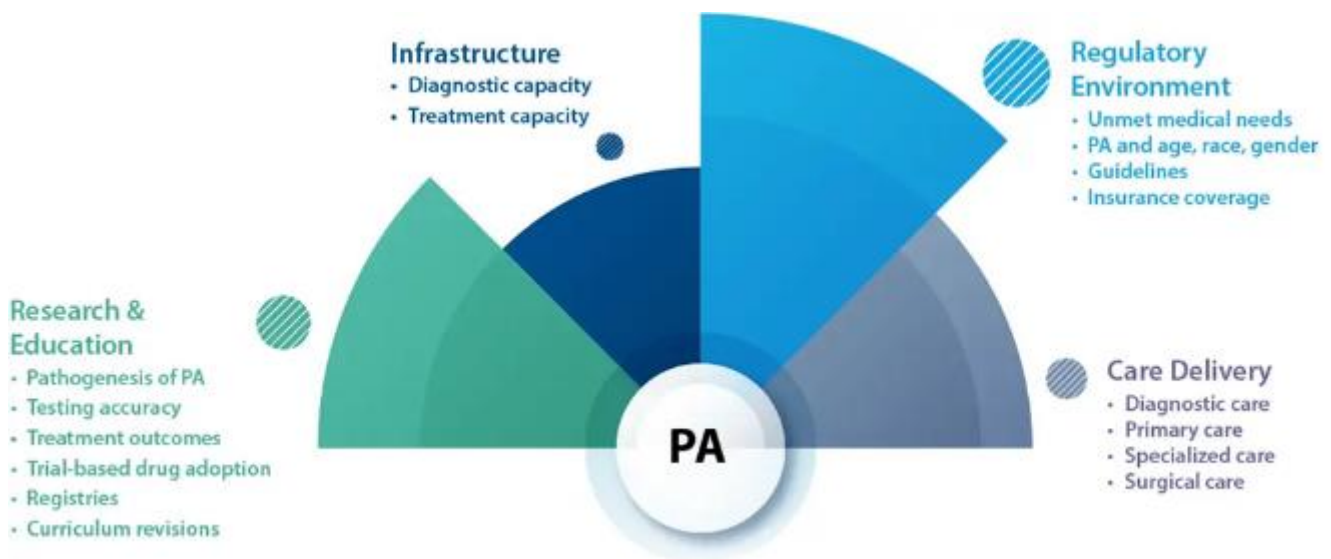
The Call to Action resulted in the creation of a *Stakeholders' Alliance* to improve standards of care of primary aldosteronism through collaborative work.



Our Programs

Successfully addressing issues with the magnitude of primary aldosteronism requires *coordinated efforts* across the entire healthcare system.

Improving standards of care of a highly prevalent disease that disproportionately affects segments of a population requires *public health interventions*.



If 95% of those affected are neither diagnosed nor treated, interventions are also needed to ensure the provision and insurance coverage of health services:

- Payment structures must allow for all diagnostic and treatment procedures for all patients,
- Barriers to diagnosis and treatment must be identified, and inclusive solutions implemented at the primary and specialized care levels,
- Accurate screening must be undertaken on a large scale, and
- Capacity must be increased at all medical centers to address unmet medical needs.

To address these issues, the Foundation has created *7 programs* focusing on the design and implementation of the following interventions:



Patient Discovery

Capacity to locate those with unmet medical needs is lacking. For over a decade, artificial intelligence has been successfully used to resolve issues such as these for various diseases. The Foundation is collaborating with healthcare systems and leaders in information technology to expedite the design and implementation of AI-based models to *find individuals* who need diagnosis and treatment.



Availability of Care

Albeit curative for 35% of patients, surgical care is nearly nonexistent, in large part because of the unavailability of adequate testing (i.e., adrenal venous sampling). In collaboration with the Foundation, two medical societies (SIRWEB and AAES) are carrying out an inventory of existing services with the aim of developing a regionally balanced pathway to *increase availability of care* at US medical centers.



Delivery of Care

The causes of clinical and therapeutic inertia remain unknown. Understanding of barriers to healthcare delivery is essential to inform the *co-creation with providers* of effective interventions to improve standards of care. Together with the Foundation, experts in primary care, relevant specialties, and implementation science are investigating the reasons for clinicians' failure to diagnose and treat primary aldosteronism. Study results will be submitted to peer reviewed journals.



Community of Practice

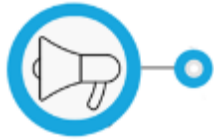
Diagnosing and treating at scale requires to build capacity through collaborative work. To help anchor this community of practice, the Foundation is developing a *physician portal* to support standardization of care with knowledge translation and sharing. The platform will offer clinicians the opportunity to gain insight into effective diagnosis and treatment, share successes and challenges, and learn from surveillance and clinical findings, as a group and in preferential ways such as direct access to ongoing clinical trials.



Patient Support

The Foundation assists those who have, or suspect they have primary aldosteronism, in navigating the road to accurate diagnosis, obtaining adequate and effective treatment, staying abreast of relevant clinical advances, and optimizing their care. With its *patient portal*, the Foundation provides users worldwide with access to:

- Knowledge translation and education,
- Personalized support, and
- Directories of physicians and centers of excellence.



Advocacy

The Foundation engages with stakeholders on an ongoing basis to influence *policies and the prioritization of primary aldosteronism* as a major public health issue. Similarly, the organization participates in the revision of clinical practice guidelines and promotes the update by medical schools of their curriculum to acknowledge high prevalence and train medical students to diagnose and treat the disease effectively.



Charters

Because the organization of healthcare varies across countries, the Foundation was initially conceived as an umbrella organization to which *national charters* would be added over time. A prototype of such charters is under development at Monash University in Victoria, Australia.

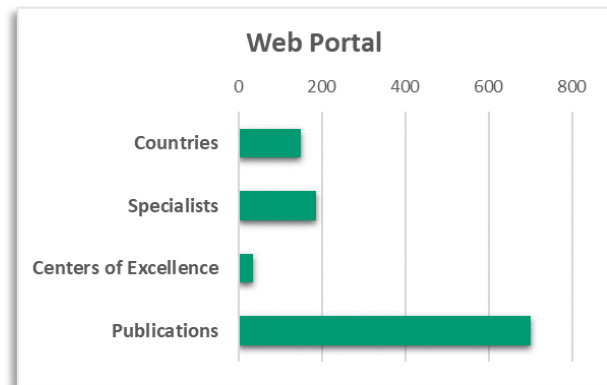
Our Progress

www.primaryaldosteronism.org

Since its launch in 2020, the website of the Primary Aldosteronism Foundation has risen to the *top sites listed by search engines* for the disease.

With over 4,000 monthly visitors from over 150 countries, the website serves as a general portal offering extensive knowledge translation, patient support and education, as well as multiple directories, including:

- Over 185 vetted specialists,
- Over 35 vetted centers of excellence, and
- Over 700 publications.



Clinical Guidelines

In November 2022, the Primary Aldosteronism Foundation was invited to participate in the revision of the clinical practice guidelines. One of the Foundation's Co-Founders represents patients at the monthly meetings of the review panel. The revision is coordinated by the Endocrine Society, and its completion is anticipated by 2025.

Availability of Care

As of November 2022, the Society of Interventional Radiology has committed to providing an inventory of adrenal venous sampling capacity in the US. The American Association of Endocrine Surgeons has joined in the effort and will overlay the data with surgical capacity. The aim of this intervention is to remediate gaps by developing a regionally balanced increase in availability of care and establishing a pathway to capacity for medical centers (e.g., formal accreditation).

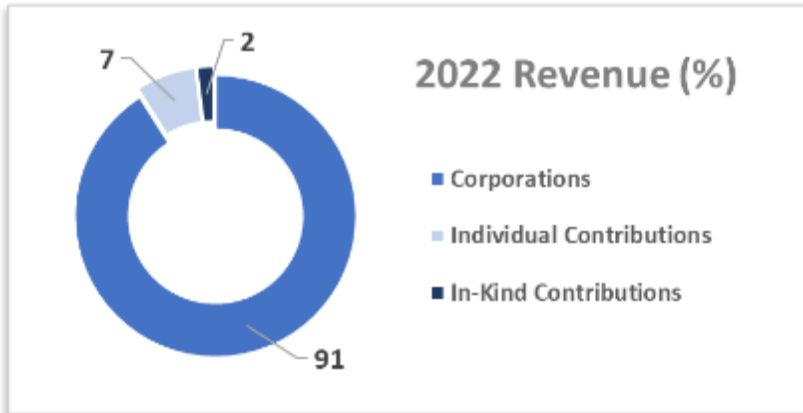
Barriers to Diagnosis and Treatment

Formal investigation of the causes of underdiagnosis and misdiagnosis by primary care physicians and specialists has never been conducted. Understanding of clinical and therapeutic inertia is essential to inform the co-creation with providers of effective interventions to improve standards of care at scale.

Together with the Foundation, clinical researchers from Yale, Vanderbilt, Monash University, and the University of Calgary are collaborating to fill this important knowledge gap. Combining expertise in implementation science research, primary care, endocrinology, cardiology, and nephrology, they will publish an opinion paper in early 2023. Preliminary results of the study are expected later in the year and will be submitted to peer review journals.

Financial Overview

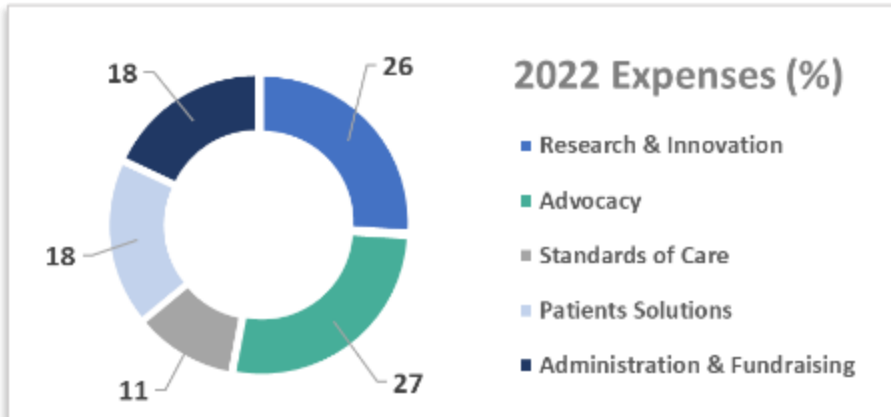
Revenue



Because it is still in early stages of development, the Foundation draws most of its revenue from corporate funding. Grant applications have been proactively pursued in 2022, and awards are expected in 2023.

Considering the very low number of diagnosed patients, although improving, individual contributions remain limited.

Expenses



In 2022, the Primary Aldosteronism Foundation dedicated over 50% of its resources to advocacy and research, followed by patients solutions at 18%, and standards of care at 11%.

While all efforts were made to contain operational costs, because of its development needs, the Foundation expended 18% of its budget on fundraising and associated administrative costs.

Statement of Financial Position

	Total
ASSETS	
Current Assets	
Bank Accounts	
Business Checking (400)	5,963.91
Business Membership Savings (000)	53,657.70
Cash on Hand	0.00
PayPal Donations Account	0.00
Total Bank Accounts	\$59,621.61
Other Current Assets	
Grants Receivable	25,000.00
Vendor deposits	5,300.00
Total Other Current Assets	\$30,300.00
Total Current Assets	\$89,921.61
TOTAL ASSETS	\$89,921.61
LIABILITIES AND EQUITY	
Liabilities	
Current Liabilities	
Accounts Payable	
Accounts Payable	5,200.00
Total Accounts Payable	\$5,200.00
Total Current Liabilities	\$5,200.00
Total Liabilities	\$5,200.00
Equity	
Opening balance equity	0.00
Retained Earnings	43,929.44
Net Revenue	40,792.17
Total Equity	\$84,721.61
TOTAL LIABILITIES AND EQUITY	\$89,921.61

Statement of Activities

	Total
Revenue	
Bank Interest	41.34
Contributions	
Corporate Contributions	80,050.00
In-Kind Contributions - Services	4,038.91
Indirect Public Support	108.41
Individual Contributions	8,028.43
Total Contributions	\$92,225.75
Sales	28.54
Total Revenue	\$92,295.63
TOTAL UNRESTRICTED INCOME	\$92,295.63
Expenditures	
Administrative Expenses	
Bank Service Charges	44.36
Business software	1,599.88
Contract Services - Admin	3,864.00
Email	280.40
Government fees	10.00
Grant acquisition expenses	269.00
Online conferencing	14.99
Training	138.00
Total Administrative Expenses	\$6,220.63
Development/Fundraising	\$2,932.00
Program Expenses	
Contract Services - Programs	39,881.16
Donations to other charities	25.00
Marketing	452.00
Website Hosting	1,142.58
Website software licenses	850.09
Total Program Expenses	\$42,350.83
Total Expenditures	\$51,503.46
Net Operating Revenue	\$40,792.17
Net Revenue	\$40,792.17

Corporate and Individual Donors

The progress made in 2022 by the Primary Aldosteronism Foundation would not have been possible without the support of its donors. Their contributions are greatly appreciated.

Corporate Donors

Start-Up Funder (\$75,000+)

Mineralys Therapeutics LLC

Sponsors of the Call to Action (\$5,000 to \$15,000)

Gold level: PhaseBio Pharmaceuticals Inc

Silver level: CinCor Pharma Inc.

Bronze level: DiaSorin S.p.A

Corporate Support (\$150+)

Amazon Smile

Corporate Matching Donations (up to \$50)

Comcast Corporation

UK Online Foundation

Individual Donors

Champions (\$5,000)

Ken Luker

Partners (\$1,000+)

Mike McGowan

Rene Moreno

Debbie Kelly

Promoters (\$100)

Anonymous (1)

Sandra Sue and Oliver Windsor

David Varner

Benefactors (\$50)

John Sakowsky

Peter James

Al and Marcia Rohrer

Supporters (\$25+)

Anonymous (1)

William Nethercott

Clarence E Grim

Governing, Managing and Scientific Boards

Governing and Managing Boards

The Foundation's Board of Directors is made up of five volunteers — **Mike McGowan, Marianne Leenaerts, Rene Moreno, Debbie Kelly, and Tanya Hanner** — who are responsible for the stability and future of the organization. They also act as Managing Directors with fiduciary, legal, and ethical responsibilities to fulfill the Foundation's mission, development, and operation.

Scientific Advisory Board

The Foundation is advised by eleven distinguished researchers and practitioners at leading academic medical centers and research institutions in Australia, Canada, Europe, and the US.

Professor Felix Beuschlein, MD

Head of Division of Endocrinology, Diabetes and Clinical Nutrition
University Hospital Zurich, Switzerland

Professor Morris J. Brown, MD, FRCP, FMedSci

Professor of Endocrine Hypertension
Queen Mary University of London, William Harvey Heart Centre, United Kingdom

Professor Robert Carey, MD, MACP

Dean, Emeritus, and University Professor
University of Virginia School of Medicine, United States

Professor Peter Fuller, MBBS, FRACP, PhD

Associate Director, Hudson Institute of Medical Research
Head, Endocrinology Unit, Monash Health, Australia

Professor Gregory A. Kline, MD, FRCPC

Clinical Professor of Medicine and Endocrinology
Cummings School of Medicine, University of Calgary, Alberta, Canada

Professor Jacques W. M. Lenders, Em, MD, PhD, FRCP

Professor of Vascular Medicine
Technische Universität Dresden, Germany; University Nijmegen, The Netherlands

Professor Michael Stowasser, MBBS, FRACP, PhD

Professor, Faculty of Medicine
The University of Queensland, Australia

Doctor Adina Florina Turcu, MD, MS

Assistant Professor of IM/MEND
Michigan Medicine Metabolism, Endocrinology and Diabetes, Oncology, United States

Doctor Anand Vaidya, MD, MMSc

Director, Center for Adrenal Disorders, Brigham & Women's Hospital
Associate Professor of Medicine, Harvard Medical School Division of Endocrinology, United States

Dr. Jun Yang, MBBS, FRACP, PhD

Research Scientist, Cardiovascular Endocrinology, Hudson Institute of Medical Research
Consultant Endocrinologist, Monash Health, Australia

Professor William F. Young, Jr., MD, MSc

Tyson Family Endocrinology Clinical Professor
Professor of Medicine, Mayo Clinic College of Medicine, United States