NATIONAL CMV FOUNDATION

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ANNUAL REPORT

2024

A YEAR OF PROGRESS, PURPOSE, AND PARTNERSHIP

www.nationalcmv.org

LETTER FROM LEADERSHIP

Dear Friends and Supporters,

As Executive Director of the National CMV Foundation, I am proud to reflect on our impactful 2024 — a year defined by bold advocacy, expanded outreach, and deepened community engagement.

In 2024 we significantly amplified advocacy and policy efforts, centering on advancing newborn CMV screening, including through state-level partnerships and hospital-based initiatives. Our aim is to ensure early diagnosis and timely intervention measures—such as antiviral therapy and developmental therapy—become standard of care for infants born with congenital CMV.

Our Education & Outreach work reached new audiences with digital campaigns, educational webinars, printed materials, and an expanded Speaker's Bureau, focusing on prevention messages for three key groups: people of childbearing age, childcare providers, and healthcare professionals.

Through the CMV Community Alliance, we nurtured volunteer groups across more than 20 states, supporting local advocacy, peer support, awareness events, and fundraising initiatives — and providing leadership training and expert engagement to empower them as ambassadors in their communities.

Meanwhile our Care to Talk online support group continued as an open, moderated space connecting CMV families—offering peer-to-peer support, sharing experiences, and helping families navigate life during and beyond diagnosis.

In fundraising and awareness, we hosted our Compete 4 CMV endurance series, including the Strides 4 CMV virtual 5K and regional challenges, and partnered with events like Walk4Hearing to amplify awareness and raise resources for research, education, and policy change.

As we look ahead, these efforts have laid a strong foundation for 2025 — propelling us toward greater awareness, policy impact, and life-changing support for families affected by congenital CMV.

With gratitude and determination,

KHALIAH FLEMING, PHD
EXECUTIVE DIRECTOR
NATIONAL CMV FOUNDATION

Mission & Vision

Our Mission

To eliminate congenital CMV (cytomegalovirus) for the next generation through education, advocacy, early detection, and improved access to intervention and support.

We are driven by the belief that every child deserves a healthy start — and every parent deserves to know how to protect their baby from CMV.

Our Vision

A world in which no child suffers from congenital CMV.

A future where prevention is widespread, screening is universal, and families have the resources and support they need from day one.

In 2024, We Focused On:

- Federal Advocacy: Introduced the bipartisan STOP CMV Act in both the U.S. House and Senate, marking a major step forward in national awareness, screening, and prevention efforts.
- Data & Systems Modernization: Upgraded internal platforms to more effectively track donations, manage events, and engage supporters with greater efficiency and insight.
- Community & Leadership Development: Strengthened connections across our Board of Directors, Scientific & Medical Advisory Committee, volunteers, and CMV community leaders to foster deeper collaboration and reach.
- Operational Efficiency: Streamlined internal workflows and resource allocation to maximize program impact while maintaining a lean organizational footprint.
- Strategic Planning: Laid the foundation for our 2024–2026 Strategic Plan, focusing on sustainability, growth, and measurable progress in awareness, research, and support.

2024 At-a-Glance

In 2024, the National CMV Foundation advanced its mission to eliminate congenital CMV through education, research, and advocacy. Thanks to our passionate community of supporters, we exceeded fundraising goals, expanded our national footprint, and empowered families and professionals alike.

Impact Highlights

- 32 CMV Community Alliance Chairs in 22 States
- Launched Care to Talk support group
- Introduced STOP CMV ACT
- Released first Position Statement
- National Organization for Rare Disorders patient registry grant awarded
- 5,300 downloads of the CMV Speaks podcast

Event Success Snapshot

Event	Net Revenue
Strides 4 CMV (Worldwide)	$37,382
Strides 4 CMV (Twin Cities)	$25,128
NYC Marathon – Team Compete4CMV	$33,874
Giving Tuesday	$24,312
Community-Led Third-Party Events	$32,638

Program Highlights

In 2024, the National CMV Foundation advanced its mission by expanding its reach, deepening community engagement, and building new pathways for advocacy and education. With support from our donors, volunteers, and partners, here's how we made an impact:

CMV Community Alliance (CCA)

30 Chairs in 22 States | $45,000+ Raised | 1,500+ Materials Distributed

Our volunteer-led CCA program continues to grow as a national grassroots force. Launched in 2019, this program equips regional volunteers to support others within their local community, increase awareness of congenital CMV, and raise critical funds to support outreach efforts of the Foundation.

- Organized 10+ local fundraising and awareness events
- Advocated for CMV legislation—4 state bills
- Engaged 40+ partner organizations and donated over 737 hours

Care To Talk

Parent support group

The Care to Talk program is a private online support group that offers a safe space for parents and caregivers impacted by congenital CMV to connect, share experiences, and access peer support. Facilitated by CMV community leaders and moderated for safety, the group helps reduce isolation and foster understanding among families navigating diagnosis and long-term outcomes. Available year-round as a free support tool from the Foundation

Program Highlights

Advancing Research

In 2024, the National CMV Foundation advanced congenital CMV research by funding early-career investigators, promoting clinical education, and elevating awareness of vaccine progress.
Key Research Highlights (2024):

- Awarded Early Career Congenital CMV Research Grants to support innovative investigations in prevention, diagnosis, and treatment.
- Promoted clinical awareness through webinars and the Public Health & Policy Conference, featuring experts on CMV-related neurodevelopment and hearing outcomes.
- Amplified scientific dialogue on CMV vaccine development, particularly around Moderna's mRNA-1647 candidate and its early clinical trial progress.
- Strengthened partnerships with researchers and institutions to align community needs with emerging scientific priorities.

CMV Speaks Podcast

5,300 downloads in 2024

In 2024, the CMV Speaks podcast featured a series of guest interviews including Patty Cutshall-Bailey, Mary Uran, Sarah Downing, and Stephanie English, along with Compete4CMV advocates Matt Partain, Jacob and John Laufer, and Carol and Tom Vereecke, discussing their personal CMV journeys, community activism, and efforts to raise awareness through events like virtual marathons and national campaigns

Scientific Advisory Committee

NCMVF is proud to be guided by a 12-member Scientific Advisory Committee (SAC). The SAC includes members with a diverse range of expertise to ensure that we fund only the highest quality research. In addition to advising our board regarding research funding, the SAC also ensures the accuracy of any material published or presented under the auspices of the Foundation

2024 SAC Achievement Highlights

- Early Career Research Award - RFA released
- Over 13,000 educational materials distributed and shipped
- NCMVF Position Statement on The Diagnosis of Congenital CMV released
- Five new educational materials were developed and published
- Over two dozen speaking engagements, increasing awareness and research about congenital CMV

Katie Feistel, PhD – Co-Chair
Senior Project Leader, The Aerospace Corporation (El Segundo, CA)

Mark Schleiss, M.D. – Co-Chair
Professor of Pediatrics; Division of Pediatric Infectious Diseases;
Investigator, Institute of Molecular Virology
University of Minnesota (Minneapolis, MN)

Suresh Boppana, MD
Professor, Department of Pediatrics, Division of Infectious Diseases
University of Alabama at Birmingham School of Medicine (Birmingham, AL)

Isabelle Boucoiran, MD, MSc
Clinical Associate Professor, Department of Obstetrics & Gynecology
CHU Sainte-Justine (Montréal, Quebec, Canada)

Karen Fowler, DrPH
Professor, Department of Pediatrics, Division of Infectious Diseases
University of Alabama at Birmingham School of Medicine (Birmingham, AL)

Soren Gantt, MPH, PhD, M.D.
Professor, Department of Microbiology, Infectiology & Immunology; Investigator,
Université de Montréal & CHU Sainte-Justine (Montreal, Quebec, Canada)

Kathleen M. Muldoon, PhD
Associate Professor, Department of Anatomy
Arizona College of Osteopathic Medicine, Midwestern University (Glendale, AZ)

Albert H. Park, M.D.
Section Chief – Pediatric Otolaryngology
University of Utah / Primary Children's Hospital (Salt Lake City, UT)

Sallie Permar, M.D, Ph.D.
Professor and Chair of Pediatrics
Weill Cornell Medical Center (New York, NY)

Megan Honor Pesch, M.D., MS
Clinical Assistant Professor; Director
University of Michigan / Michigan Medicine (Ann Arbor, MI)

Cedric Pritchett, M.D.
Associate Professor of Otolaryngology; Division of Otolaryngology, Department of Surgery
Nemours Children's Hospital & University of Central Florida College of Medicine (Orlando, FL)

Angela Shoup, PhD, FNAP
Professor, Otolaryngology; Chief, Division of Communicative & Vestibular Disorders UT South