2018 Annual Report

Strategic Program Investments

www.NationalCMV.org
OUR MISSION

To educate women of childbearing age about congenital CMV.
Dear National CMV Foundation Community,

Thanks to your support, 2018 was a year of unprecedented growth for the National CMV Foundation (NCMVF). We hired two inaugural staff members, piloted two new programs, sponsored two national and one global conference, and expanded our offerings to include public health awareness mini grants and early career research awards. None of this would have been possible without cash donations and in-kind gifts totaling more than $238,000. Your generous contributions have helped establish NCMVF as the leading national, nonprofit organization determined to educate women of childbearing age about congenital cytomegalovirus (CMV).

Per your support, we will continue to:

♥ Develop fresh materials and co-brand existing resources for widespread distribution
♥ Advise industry partners regarding the parent perspective to help improve policies and protocols
♥ Extend our speaker’s bureau arm to amplify reach at important meetings and conferences
♥ Address parents’ and patients’ concerns through our digital channels
♥ Provide legislative support to state-specific working groups
♥ Facilitate dialogue between healthcare providers, clinicians, parents, and volunteers
♥ Advocate for prevention education, newborn screening, and vaccine development

Our Directors include parents, advocates, clinicians, and researchers, and they join me in extending a heartfelt thank you for your generosity and partnership.

With gratitude, Kristen Hutchinson Spytek
NATIONAL CMV FOUNDATION BY THE NUMBERS

- **Years Young**: 5
- **Co-Founders**: 6
- **Board of Directors**: 9
- **Staff Members**: 2
- **Active Volunteers**: 60
- **States with CMV Champions**: 50
- **Social Media Followers**: 19K
- **Average Monthly Unique Visitors**: 25K

OUR 2018 DOLLARS AT WORK

- **$35K** to Early Career Research Funding
- **$229K** in Public Health Awareness Activities and Grants
86% of expenditures were devoted to awareness and education programs.
2018 HIGHLIGHTS

Early Hearing Detection & Intervention Annual Meeting
In March, National CMV Foundation was a bronze level sponsor and presenter at the EHDI Annual Meeting in Denver, CO. The meeting was attended by nearly 2,000 audiologists, physicians, families, early intervention specialists, speech-language pathologists, advocates, non-profits, and students.

CMV Awareness Month
In June, the CMV Community made a major impact. CMV Awareness Ribbon Kits, sponsored by Meridian Bioscience Inc. were distributed across the country and CMV Advocates nationwide hosted community fundraising events and virtual campaigns to raise over $20K.

Public Health & Policy Conference
In September, this conference brought together scientists, researchers, policy makers, parents, and state public health officials to discuss public health and policy related to CMV. National CMV was a platinum level sponsor, exhibitor, and presenter at this 400+ person meeting.
NYC Marathon Compete 4 CMV

In November, the inaugural Compete 4 CMV - NYC Marathon team ran 26.2 miles through the 5 Boroughs for CMV Awareness. The National CMV NYC community was out in force to support the runners and the cause. In total, these runners and their supporters raised over $65K.

My Cause, My Cleats Campaign

During week 13 of NFL season, players across the league wore custom cleats reflecting their commitment to charitable causes. Tampa Bay Buccaneers’ Ali Marpet (G) and Alex Cappa (OL), plus executive staff and team ownership all wore #4EVS #STOPCMV cleats to spread CMV Awareness.

FDA Authorizes the Alethia CMV Assay Test System

Meridian Bioscience, Inc. received FDA clearance for its Alethia™ CMV Molecular Amplification Test. This assay is designed to specifically detect congenital cytomegalovirus (cCMV) infection in newborns from an easy-to collect saliva sample. Alethia™ CMV is the first qualitative test in a molecular amplification format, FDA-cleared for cCMV testing in newborns. Diagnosis can be attained by detecting the virus in a baby’s saliva or urine within 2 to 3 weeks from birth. Early detection is critical in establishing appropriate treatment and intervention protocol.
The National CMV Foundation’s mission includes supporting relevant, timely and innovative research that will assist the foundation in meeting its goals to eliminate the harmful effects of maternal and congenital cytomegalovirus (CMV) infection.

**Early Career Congenital CMV Research Award**

Dr. Paul Lantos, a pediatric infectious disease specialist in Durham, NC affiliated with Duke Children’s Hospital and Health Center is National CMV’s 2018 Early Career CMV Research Award recipient.

Dr. Lantos’ project titled “Geostatistically-guided decision modeling to reduce health disparities from congenital cytomegalovirus” is significant to the field because it is the first geospatial study of congenital CMV, which will offer clear public health and cost-saving benefits from broader impacts of differential effect of congenital CMV screening in high-risk areas.

**Pediatric Infectious Disease Society (PIDS) CMV Fellowship Award for CMV Research**

The PIDS Fellowship Award for CMV Research, established by the National CMV Foundation, specifically funds Pediatric Infectious Disease basic or clinical research focused on congenital cytomegalovirus (CMV).

In 2018, Frances Saccoccio, MD, PhD, pediatric infectious disease fellow at Duke University, received year two funding. Dr. Saccoccio studies women who have a primary infection during pregnancy to examine their immune response to the infection. This will help us better understand what may help prevent transmission of CMV from an infected pregnant woman to the fetus. Determining immune responses that quickly control viral replication during pregnancy will lead to the development of new CMV vaccine targets.
2018 GRANT AWARDS

Public Health Awareness Mini Grants

The Public Health Awareness Mini Grant program exists to further promote education to medical professionals and the general public through greater, local grassroots engagement. In 2018, three projects were funded.

Raising Awareness of Congenital CMV in New Jersey

The Central Jersey Family Health Consortium (CJFHC), led by Allison Goldschlag-Reinking and Laurie Navin, mission is to improve the health of women of childbearing age, infants and children in the region through the collaborative efforts of member hospitals, providers and consumers.

The opportunity to launch a CMV campaign will help them to not only raise awareness, promote behaviors that prevent infection as well as early detection -- critical steps in improving the health of our moms and their children.

Raising Awareness of CMV in Arizona: Developing and Field Testing Educational Materials

The EAR Foundation in AZ ("EFAz"), led by Executive Director, Melissa Selbt, MPH, will build the CMV Awareness effort in Arizona, including developing policy and guidance and incorporating CMV education as part of EFA professional and client education.

The Ohio CMV Advocacy Project (OCAP)

The OCAP team's project, led by Teresa Bowman and Heather Innis, and in partnership with Ohio Hands & Voices, includes a multi-month outdoor billboard campaign in targeted demographic areas, prevention education activities geared towards childcare workers, and select meetings with Ohio legislators to discuss education and congenital CMV screening at the state-level.
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Our entire community of parents, advocates, clinicians, and researchers, extend a heartfelt thank you for your generosity and partnership.

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OUR MISSION

To educate women of childbearing age about congenital cmv.

Thank you so much for your continued support, our work would not be possible without you.