Grassroots Engagement

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iNTRO

About Us

Farah Armstrong

Chair, Programs & Education Committee

Sara Menlove Doutre

Chair, Scientific Advisory Committee

Kristen Hutchinson Spytek

Chair, President National CMV

CORE VALUES

From the President…

“There is only one word acceptable for success in the fight against congenital CMV. ELIMINATION!

We are determined to make this happen for the next generation so babies are no longer born with cognitive or developmental disability due to congenital CMV. This agenda is only achievable with the united efforts from our team of Staff, Directors, Donors, Clinicians, Scientists, Partner Organizations, and Parent Community.

We’re an eager, passionate, resilient group. We can accomplish anything, together as a TEAM.”

Kristen Hutchinson Spytek

Strategic Plan

Programs & Education

Call to Action

Breakouts

About the National CMV Foundation

Our PURPOSE is to prevent CMV infection in women of childbearing age by:

- Empowering women, parents, families, and local community networks through grassroots engagement to facilitate conversation and champion the cause.
- Delivering consistent, clear messaging and evidence-based data that aids in prevention, educates the public and increases its understanding of congenital CMV.
- Influencing CMV research priorities regarding CMV prevention, treatment and intervention.
- Advocating for a CMV vaccine.

STRATEGIC PLAN

Primary Goals: Programs & Education

Steadily increase National CMV's influence with policymakers to achieve established federal and state policy priorities by executing successful strategies to develop productive and meaningful relationships.

Establish an ambassador program by 2020 and provide public health outreach education to serve both medical professionals and the general public through greater grassroots engagement.

Priority Activities

1. Increase state priority-driven meetings between National CMV committee and volunteer representatives, and members of state government nationwide by 5% each year. At the federal level, initiate an annual trip to the Hill with a growing, volunteer powered CMV Congressional Team, beginning 2019.
2. Establish mini grant program for up to 10 State Departments of Health or similar NPO organizations by 2020, to further promote education to medical professionals and the general public through greater, local grassroots engagement.
3. Develop Ambassador Program for top CMV advocates by 2020.
4. Create instructional materials for implementing a Hearing-Targeted CMV Screening Program.

PROGRAMS AND EDUCATION

Chair: Farah Armstrong

Legislative Support

Amy Horton (Lead), Amanda Devereaux, Sara Doutre, Sara Beth Myers, Erica Steadman, Laura Sweet

Ambassador Program

Kristen Spytek (Lead), Farah Armstrong, Kristel Jacobson

Public Health Awareness Mini Grants

Alyson Ward (Lead), Farah Armstrong, Kirsten Coverstone, Stephanie McVicar

Strategic Partnerships

Brittany Anderson, Rebekah McGill

Education & Outreach

Farah Armstrong (Lead), Dr. Stuart Adler, Brittany Anderson, Dr. Brenda Balch,, Nellie Brown, Dr. Kimberly Carter, Mary Katherine Catignani, Kathleen Cienkowski, Cara Gluck, Dr. Gail Demmler-Harrison, Sheila Dollard, Kim Hill, Stephanie McVicar, Kathleen Muldoon, Dr. Albert Park, Jessica Rachels, Sandra Salerno, Lisa Saunders, Andrea Stambaugh, Peyton Stephens, Casey Turovac

Workgroup #1: General Public Education & Outreach

Kristen Spytek (Lead)

Workgroup #2: Childcare Providers Education & Outreach

Lisa Saunders (Lead)

Workgroup #3: HCP Providers Education & Outreach

Dr. Carter & Dr. Demmler (Co-Leads)

Priority Activities: Education + Outreach

KEY OBJECTIVE: Increase cCMV awareness among our primary target audiences:

1. General public & women of childbearing age
2. Childcare providers
3. Healthcare providers

TASKS

Educational Materials

Parent & Caregiver Database

Registry of Medical Providers

Hearing Targeted CMV Screening Education

IMPACT & REACH

Utilize expertise and experience within our workgroups to drive more effective educational campaigns to reach our target audiences, at scale.

SUPPORT NEEDED

Consistent fundraising to increase the revenue streams available to support our existing & future programs.

PROGRAMS & EDUCATION

Priority Activities: Legislative Support

KEY OBJECTIVE: Steadily increase National CMV's influence with policy makers.

TASKS

Develop interactive map

Establish State Directory

Support legislative leads in states with legislation

Create new resources

IMPACT & REACH

Achieve federal and state policy priorities

Gain federal funding

SUPPORT NEEDED

Identify contacts for State Directory

Recruit additional committee members

PROGRAMS & EDUCATION

Priority Activities: Public Health Awareness Mini Grants

KEY OBJECTIVE: Funding projects that will increase cCMV awareness in the United States.

TASKS

Conducted an RFP in June.

Awarded 3 mini grants to non-profit organizations that further propel our mission and vision.

IMPACT & REACH

Leverages expertise, contacts, and resources from other organizations which extends both the optics & reach of NCMVF.

SUPPORT NEEDED

Advertising future RFP to contacts and partners in your State.

Priority Activities: Strategic Partnerships

KEY OBJECTIVE: Collaborating with key stakeholders to further our mission of educating women of childbearing age about congenital CMV.

TASKS

Develop interesting & dynamic relationships

Determine potential long-term partners for growth

Seek opportunities to collaborate with stakeholders

IMPACT & REACH

Extending our reach to new audiences through stakeholder contacts

CHALLENGES

Need additional committee members to take innovative approach to reaching new audiences & funding key initiatives

CALL TO ACTION

CMV Community Alliance

PURPOSE: State-level extension of existing programs.
Local street team representing National CMV and furthering its mission.

AREAS OF FOCUS

Active fundraising

Primary point of contact for local individuals and families

Conducting education & outreach to increase exposure to new audiences

IMPACT

Reaching new audiences

Increase awareness of CMV at the state level

Decrease the incidence rate of CMV at state level

SUPPORT NEEDED

Eager volunteers willing to lead, with proven track record

CALL TO ACTION

CMV Community Alliance

What does this look like?

- Program of NCMVF – guided by Programs & Education committee
- Each CCA operates independently within national framework set forth by NCMVF and in collaboration with fellow alliances
- Knowledge, tools, best practices, etc. are shared among the CCA network. NCMVF will facilitate sharing through webinars, meeting, and in-person events
- A local CCA is formed by first appointing a CCA Chair
- Chair is main point of contact for NCMVF staff and ultimate owner of roles and responsibilities
- Chair recruits fellow, local Ambassadors to form working groups

CALL TO ACTION

CMV Community Alliance

Community Alliance Chair Responsibilities:

- First point of contact for individuals and families seeking more information on:
  - local advocacy initiatives
  - awareness and fundraising events
  - meetings
- Conduct 3 events annually – 1 fundraiser, 1 social gathering, 1 educational event
- Manage operational budget provided by NCMVF
- Recruit volunteer ambassadors for project-specific support
- Participate in quarterly NCMVF ‘State of CMV’ conference calls to up-to-date with latest information regarding NCMVF events, news, and resources
- Engage in monthly 1:1 meetings with NCMVF staff person for training and collaboration
- Submit a monthly status report to the NCMVF staff person

CALL TO ACTION

CMV Community Alliance

Benefits

- A staff person to serve as your main contact for guidance, assistance, and resources
- Use of NCMVF logo and name
- A copy of NCMVF's 501(c)(3) tax exempt letter and federal tax identification number
- Access to a constituent list within your state
- General liability insurance coverage
- Monthly conference calls to be held 1:1 with staff member for review and planning
- Quarterly group conference calls for all ambassadors for collaboration, development, and training
- Support in creating emails, newsletters, invites, registration pages to support and market your local activities
- Invitation to attend an annual, in-person meeting for training and idea sharing
- Budget to offset specific event and education costs
- A NCMVF email address & business cards

CALL TO ACTION

CMV Community Alliance

2019 Pilot Program

- Launch five CMV Community Alliances as initial pilot program
- Criteria for selection of Chairs:
  - Nomination process
  - Active community members with strong partnerships in their region
  - Proven track records in fundraising
  - Active in community – creating awareness, hosting events, presenting at conferences, leading legislative efforts, forging strategic partnerships
- Fundraising minimum $5k per year

BREAKOUTS

Self-directed Exercises

1. Know Your Facts – CMV Elevator Pitch

2. Know Your Story – Personalize it. Why Are You Connected to & Passionate About the Cause?

3. Identify 10 people within your network that you would contact to contribute, support, and inform about this organization

4. Identify 3 organizations, corporations or institutions that you can contact to recruit volunteers or funding (e.g. grants, sponsorships, employee matching)

BREAKOUTS

Next Steps & Timing

1. November 27th – #GivingTuesday – A Global Giving Movement
2. January 1st – Launch CMV Community Alliance
3. April 7th – International CMV Conference in Birmingham, AL

Contact us.

Get involved! Join us today.

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Thank You.