# Chapter Champions Orientation Guide

## Table of Contents

### SECTION 1: Welcome and Program Introduction/Overview

- Welcome Letter ............................................................................................................................................ 5
- Program Overview ....................................................................................................................................... 6
- Chapter Champions Engagement Overview ................................................................................................ 7
- Chapter Champions “Top Five Ideas to Get Started” ................................................................................. 9
- Chapter Champions: Ideas for How to Be Engaged .................................................................................... 10
- Chapter Champion Year 1 Work Plan (template) ....................................................................................... 15
- Chapter Champions Roster ......................................................................................................................... 17
- Project Advisory Committee Roster ........................................................................................................... 19
- Quality Improvement Expert Group Roster ................................................................................................. 20
- Project Advisory Committee/Chapter Champion Regional Assignments Grid ......................................... 21
- AAP District Map ......................................................................................................................................... 22
- Program Funder Information – Allergy and Asthma Network ................................................................. 23

### SECTION 2: How to Connect and Work with Your Chapter

- About AAP Chapters ................................................................................................................................... 25
- 2014 AAP Chapter Presidents ..................................................................................................................... 26
- 2014 AAP Chapter Vice Presidents ............................................................................................................ 29
- 2014 AAP Chapter Executive Directors ................................................................................................... 32
- Steps for Communicating with Chapter Leadership ................................................................................... 35
SECTION 3: State and Local Advocacy and Partnerships

Building Effective Partnerships ................................................................. 37
AAP Advocacy Presentation ..................................................................... 39
Getting to Know Title V ......................................................................... 65
Title V: Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) State Contacts ......................................................................................................................... 86
Children’s Health Insurance Program (CHIP) State Directors ............... 96
National Association of State Medicaid Directors Membership List .... 99
Section 1
Dear AAP Medical Home Chapter Champion,

In 2008, the American Academy of Pediatrics implemented the Medical Home Chapter Champions Program on Asthma (MHCCPA) to support Chapters in applying the principles of Medical Home to the care of one of the most common chronic conditions in children. In 2014, the program was expanded to include the care of children with allergy and anaphylaxis (now MHCCPAAA) and to focus further on quality improvement, policy, and advocacy. As part of this Program, the Academy has sought to identify at least one pediatrician in each chapter to “champion the cause.”

More than 50 chapter champions have been recruited, some of whom participated in the previous asthma-focused phase of the program. The new project is funded by the Allergy and Asthma Network (AAN, aanma.org), which will also collaborate on its implementation. The Project Advisory Committee (PAC) staff will encourage and support the Champions to be engaged in asthma, allergy and/or anaphylaxis-related activities in their states and in coordinating efforts to promote optimal care for those conditions within Medical Homes and the broader “Medical Neighborhood.” The previous project emphasized networking and education; the new project will add quality improvement, policy, and advocacy foci.

Please review the attached orientation guide to acquaint yourself with the potential roles of chapter champions and the support available to you. Note that champions receive a monthly e-newsletter, with information about current studies, upcoming opportunities/events, helpful resources, and more.

We want your feedback and suggestions on how to best meet your needs. Please do not hesitate to contact the AAP staff or your assigned AAP Regional PAC member with your thoughts. Be sure to visit the program Web site for more medical home, asthma, allergy, and anaphylaxis resources at http://www.aap.org/en-us/professional-resources/practice-support/medicalhome/Pages/Asthma-Allergy-and-Anaphylaxis.aspx.

Thank you for your commitment to helping kids and working with us to improve their care.

Sincerely,

Chuck Norlin, MD, FAAP
Chairperson, Project Advisory Committee (PAC)
Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis
Background
The American Academy of Pediatrics (AAP) established the Medical Home Chapter Champions Program on Asthma (MHCCPA) to meet an identified need for the development of a high-impact, national initiative focused on improved quality care of pediatric patients with asthma, including the facilitated implementation of the National Heart, Lung, and Blood Institute (NHLBI) 2007 asthma guidelines within medical homes. The MHCCPA has since served as an effective conduit for dissemination of best practices and advocacy for implementation of the NHLBI asthma guidelines within medical homes at the AAP chapter and/or state level(s).

Through the generous support of the Allergy & Asthma Network Mothers of Asthmatics, the Academy will embark on a new, two-year initiative expanding both the focus of the program—to include asthma, allergy and anaphylaxis—and its activities towards achieving improved health outcomes for children.

Program Goal and Objectives
• To improve outcomes for all children with asthma, allergy and anaphylaxis via the provision of comprehensive team-based, family-centered care and effective co-management between primary and subspecialty care settings.
• To achieve this goal, the project will: support a successful, national chapter champion network model; initiate a team-based, care coordination and co-management quality improvement effort; and cultivate an enhanced focus on advocacy and policy.

Program Components
Chapter Champions Network - Program objectives will be addressed through the established Medical Home Chapter Champions network with representation from each AAP chapter. Chapter Champions will: serve as a conduit for disseminating best policies and practices to pediatric health care providers nationwide through the leadership and networks of AAP chapters; serve as advocates for change at the local, state, and national levels; become involved in providing technical assistance, as well as tools and resources to pediatricians and other pediatric health care providers; and assist in aligning national and state, local, and/or community priorities.

Quality Improvement Learning Community - Using both a web-based (virtual) learning initiative and a quality improvement learning collaborative approach, the program will develop, enhance and test tools that support the interface between primary care pediatricians and pediatric subspecialists in team-based provision of asthma, allergy and anaphylaxis care. An additional goal of this component of the project will be to optimize the role of the primary care physician while ensuring appropriate referrals to subspecialists.

Policy Change - Policy change that supports implementation of family-centered asthma, allergy and anaphylaxis care will be advanced and facilitated at the community, chapter and state levels through the provision of educational and other materials and support for cross-sector collaboration.

For more information, contact: Nkem Chineme, MPH, Program Manager, Medical Home Chapter Champions Program on Asthma, Allergy & Anaphylaxis, Division of Children with Special Needs, at 847.434.4342 or nchineme@aap.org
Chapter Champions Engagement Overview

Medical Home Chapter Champions Network
Across the American Academy of Pediatrics (AAP), chapter champion programs have been very effective for dissemination of best policies and practices to pediatric health care providers and others nationwide. The overarching goal of these programs is to enhance the leadership and volunteer networks of AAP chapters. Chapter champion programs also serve as a mechanism by which pediatricians can advocate for change at the local, state, and national levels. AAP chapter champion programs managed at the national level focus on establishing infrastructure to provide technical assistance as well as tools and resources to pediatricians and other pediatric health care providers in a more direct manner. As a result, activities can be developed that align more closely with state, local, and/or community priorities. To this end, the medical home chapter champions network is dedicated to advancing the core components of patient- and family-centered medical home for children with asthma, allergy and anaphylaxis, and their families at the state and local level.

Overview of the Medical Home Chapter Champions Program
In 2010, the AAP established the Medical Home Chapter Champions Program on Asthma (MHCCPA) to meet an identified need for the development of a high-impact, national initiative focused on improved quality care of pediatric patients with asthma, including the facilitated implementation of the National Heart, Lung, and Blood Institute (NHLBI) 2007 asthma guidelines within medical homes. The MHCCPA has since served as an effective conduit for dissemination of best practices and advocacy for implementation of the NHLBI asthma guidelines within medical homes at the AAP chapter and/or state level(s).

Through the generous support of the Allergy & Asthma Network (AAN), the AAP will embark on a new, two-year initiative, the Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis (Medical Home Chapter Champions program), expanding both the focus of the program—to include allergy and anaphylaxis—and its activities towards achieving improved health outcomes for children. The aim of the Medical Home Chapter Champions program is to promote the delivery of high quality asthma and allergy care in the medical home through team-based, family-centered care coordination and co-management among patients and their families, primary care pediatricians, and pediatric asthma and allergy specialists.
Program goals include:

- Support the chapter champions’ network via the coordination and implementation of educational and quality improvement initiatives as well as the provision of ongoing technical assistance to same;
- Provide specific programmatic activities centered around enhanced communication, coordination and collaboration between patients and their families, pediatric primary care providers and subspecialists; and
- Support policy and advocacy efforts at the local, state and national levels.

Role and Responsibilities of Medical Home Chapter Champions

The role of the AAP Medical Home Chapter Champion (MHCC) is completely voluntary. The responsibilities and initiatives of the chapter champions can be diverse.

These individuals:

- Are dedicated, eager, and energetic; they are committed to improving systems and outcomes related to children with asthma, allergy and/or anaphylaxis at the local, state and chapter levels;
- Serve as a conduit for disseminating best policies, practices and education, as well as other resources and information, to pediatric health care providers in their chapter/state.
- Serve as an advocate for change related to medical home and/or asthma and allergy care at the local, state, and national levels.
- Participate in a series of educational webinars.
- Participate in regional conference calls periodically to further knowledge and education on various topics important to the program.
- Potentially participate in quality improvement initiatives to improve communication and co-management between generalists and pediatric subspecialists.
- Receive via a monthly e-newsletter updates on news, information and resources on medical home and/or asthma and allergy care.
- Enhance and facilitate networking between and among chapter champions.
- Assist in aligning national, state, local, and/or community priorities.
- Learn proven ways to implement and improve medical-homeness.
- Learn from national experts and peers engaging in medical home quality improvement efforts.
- Access practical tools and strategies for how to deliver better patient- and family-centered care.

AAP Contact Information

Nkem Chineme, MPH
Program Manager
Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis
nchineme@aap.org
847/434-4342
Medical Home Chapter Champion

TOP 5 IDEAS TO GET STARTED

1. **Complete Year 1 Chapter Champion Work Plan** (and submit to Nkem Chineme at nchineme@aap.org)

2. Make sure to review the course content and sign up for the asthma OR medical home* EQIPP course (courses are complimentary for AAP members!) In addition, engage others in your practice in a possible small-scale quality improvement effort by taking the EQIPP course together.

3. Visit the "Building Your Medical Home" resource to download tools and resources as you begin your practice transformation. ([www.pediatricmedhome.org](http://www.pediatricmedhome.org))

4. Connect with your Chapter President, Chapter Vice President and Executive Director (see “Steps for Communicating with Chapter Leadership” in section 2 of the orientation guide)

5. Contact one of your state’s Title V leaders to introduce yourself and let them know what you are working on. Find out how you can collaborate on medical home, asthma, allergy and anaphylaxis activities and initiatives (see “Getting to Know Title V” and “Title V State Contacts” in section 3 of the orientation guide)

*Medical home in primary pediatric care EQIPP course coming soon. Sign up to be notified when it is available at [http://eqipp.aap.org/](http://eqipp.aap.org/)
# Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis

## Chapter Champions:
### IDEAS FOR HOW TO BE ENGAGED

<table>
<thead>
<tr>
<th>EDUCATION</th>
<th>Activities</th>
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| **Participate in opportunities for education on medical home, and asthma, allergy and anaphylaxis management within the medical home, and share these opportunities with pediatricians and other stakeholders in your chapter/state** | 1. Participate in the program’s educational webinar series  
   - Submit suggestions for webinars; share relevant information/resources acquired through webinars with chapter constituencys |
|                                                                            | **Further Implementation Ideas**                                                                                                                 |
|                                                                            | - Stay “current”—to the extent possible—on Academy and other medical home and asthma, allergy and/or anaphylaxis initiatives via AAP News, the Medical Home Chapter Champions listserv, National Center for Medical Home Implementation listserv and other opportunities available to AAP members-at-large |
|                                                                            | - Subscribe to receive The MA Report, the Allergy and Asthma Network’s flagship newsletter by emailing editor@aanma.org               |
|                                                                            | - Promote educational webinar series to chapter leaders, staff, members and other key stakeholders in your practice and state |

2. Ensure that you have a good understanding of educational opportunities in your chapter/state as they relate to medical home and asthma, allergy and anaphylaxis management, such as:  
   - Chapter annual (and other educational) meetings  
   - Hospital grand rounds/residency training opportunities  
   - Chapter and/or state-wide webinars, other educational seminars  

**Further Implementation Ideas**  
- Work with your Chapter Executive Director and/or chapter staff to compile a list of educational opportunities (such as those mentioned above) if one does not already exist; update this list periodically and share with others  
- Join appropriate listservs and/or visit related Web sites periodically to ensure continued awareness of such opportunities  
- Participate in grand rounds or other hospital-based or residency training presentation on management of asthma, allergy and/or anaphylaxis in the medical home

3. Provide technical assistance and share/disseminate tools and resources, to pediatricians and other pediatric health care providers in your state through various means such as e-mail, phone/conference calls and speaking at educational events  

**Further Implementation Ideas**
• Reach out to your chapter and introduce yourself to staff
• Request that your chapter lists your name and contact information on the chapter Web site as the chapter champion for the Medical Home Chapter Champion Program on Asthma, Allergy and Anaphylaxis
• Suggest that your chapter link to the AAP Medical Home Chapter Champions Web page [http://www.aap.org/en-us/professional-resources/practice-support/medicalhome/Pages/Asthma-Allergy-and-Anaphylaxis.aspx]
• Submit “ghost written” articles provided by PAC and program staff on program-related topics to chapter newsletters, Web site, etc. (You may need to contact your chapter staff to learn when newsletters are published and what their respective due dates are.)
• Offer to conduct a training program or workshop at a chapter educational meeting or chapter medical home learning session

4. Register for the Education in Quality Improvement in Pediatric Practice (EQIPP)
   • The Asthma EQIPP course was recently updated and is available free as a member benefit to all AAP members
   • If you feel comfortable with asthma management, explore other EQIPP [http://eqipp.aap.org/] or PediaLink [http://pedialink.aap.org/visitor/home] courses; available as a member benefit

Further Implementation Ideas
• Contact another chapter champion or group of champions and enroll in the courses at the same time to compare results and engage in group process feedback

ADVOCACY/POLICY

Serve as an advocate for change related to medical home and/or asthma, allergy and anaphylaxis at the local and state levels

1. Work with chapter leadership in disseminating existing asthma, allergy and anaphylaxis care best practices

Further Implementation Ideas
• Talk to your chapter Executive Director, President and/or Vice President about any past needs assessments conducted by the chapter and how you can access the data obtained
• If a needs assessment has not yet been done, start a discussion with the leadership about the benefits of conducting one and/or offer to draft one and to be involved in reviewing and analyzing the results
• If a needs assessment has been conducted, work with your chapter leadership to identify how the identified needs can be incorporated into the chapter’s advocacy agenda

2. Determine if there are any medical home demonstration projects/initiatives in your state (Medicaid or otherwise) [http://www.medicalhomeinfo.org/state_pages/]; find out how you can get involved
Further Implementation Ideas

- Work with your chapter to contact the medical directors or key staff at major insurance companies/plans in your state to engage in discussions related to medical home and/or asthma, allergy and anaphylaxis
- Visit the Patient Centered Primary Care Collaborative’s Primary Care Innovations and PCMH Map located here http://www.pcpcc.org/initiatives to find medical home demonstration projects/initiatives in your state
- Visit the National Academy for State Health Policy’s interactive map of state efforts to advance medical homes for Medicaid and CHIP participants, http://www.nashp.org/med-home-map

3. Find out which other organizations exist in your state/region, related to asthma, allergy and anaphylaxis or medical home (i.e., local or state asthma or allergy coalitions)

Further Implementation Ideas

- Ask your Chapter Executive Director and/or Chapter staff to let you know if they have any relationships with any key asthma and/or allergy/medical home groups in the state. If so, ask to get involved with any existing efforts
- Set up a meeting with your local or state asthma and/or allergy coalitions to share information about your role as chapter champion and determine possible areas for collaboration

4. Determine if your state is pursuing medical home, asthma, allergy and/or anaphylaxis legislation and find out how you can get involved and serve as the "voice" for pediatrics

Further Implementation Ideas

- Visit your state’s Department of Public Health Web site and/or state Medicaid agency Web site and perform a search using the key words “advocacy”, “medical home” and/or “asthma”, “allergy” and/or “anaphylaxis”
- Visit your Chapter’s Web site and look/search under “advocacy”
- Determine whether your chapter has an advocacy committee and/or Pediatric Council and consider joining it, if possible
- Position yourself as an advocate on medical home and/or asthma, allergy, and anaphylaxis issues at the state and/or federal levels
- Visit www.aap.org/stateview to view the weekly digest of StateView. StateView compiles up-to-date information on state policy trends and resources.
- Register to receive e-newsletters from the National Academy for State Health Policy (NASHP) (www.nashp.org/enews) and/or the Center for Health Care Strategies (CHCS) (www.chcs.org/); share information with stakeholders at the local and state levels
5. Collaborate with the state Title V and Medicaid staff and others in state government agencies on medical home, asthma, allergy and anaphylaxis activities and initiatives

**Further Implementation Ideas**

- Contact your state’s Title V director to introduce yourself and let them know what you are working on. You can access their contact information here: [http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/StateProfiles.aspx](http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/StateProfiles.aspx) or see the list in your orientation guide
- Contact your state’s Medicaid director to introduce yourself and let them know what you are working on. You can access their contact information here: [http://medicaiddirectors.org/about/state-directors](http://medicaiddirectors.org/about/state-directors)
- Consider attending a state-level Title V or Medicaid meeting on behalf of your chapter
- Become a resource to chapter members on issues related to Title V and/or Medicaid

<table>
<thead>
<tr>
<th>COMMUNICATIONS</th>
<th>Activities</th>
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<tr>
<td><strong>Serve as a conduit for disseminating best policies, practices and education, as well as other resources and information, to pediatric health care providers in your chapter/state</strong></td>
<td>1. Participate in periodic communication (approximately 2-3 times/year) with “assigned” Project Advisory Committee (PAC) member and other chapter champions in your region for information sharing</td>
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<tr>
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<td>2. Serve as your state/chapter’s point person for pediatric providers requesting additional information or assistance about implementing core medical home principles and/or asthma, allergy and anaphylaxis guidelines at the practice level</td>
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<td>3. Submit “ghost written” articles provided by PAC and program staff on program-related topics to chapter newsletters, Web site, etc. (You may need to contact your chapter staff to learn when newsletters are published and what their respective due dates are.)</td>
</tr>
</tbody>
</table>
| | 4. Share information and resources from the Medical Home Chapter Champions listerv and/or Chapter Champions E-News (*Champion E-Correspondence*) with colleagues, chapter leaders and members; ask them for ideas for inclusion in future issues of the *Champion E-Correspondence*

<table>
<thead>
<tr>
<th>QUALITY IMPROVEMENT</th>
<th>Activities</th>
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<tbody>
<tr>
<td><strong>Potentially participate in a web-based (virtual) learning initiative (Web&amp;ACTION model) and a quality</strong></td>
<td>1. Participate in web-based (virtual) learning initiative (Web&amp;ACTION model)</td>
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<td>- Participate in three webinars presenting practice guidelines, recommendations and tools related to communication and co-management in pediatric asthma, allergy and anaphylaxis care</td>
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<td>- Test tools and strategies during the action periods that follow each webinar and measure the impact of same</td>
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| **improvement learning collaborative (Breakthrough Series model)** | **Participate in one check-in call during each action period (three total) with Quality Improvement expert group**  
**Participate in pre/post surveys assessing virtual learning initiative impact** |
|---------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
| **2. Participate in a quality improvement learning collaborative (Breakthrough Series model)** | **Create a project team including a parent/family representative**  
**Identify changes that can be made in practice to promote the medical home model and improve care**  
**Engage in ongoing tests of change and collect data to measure these changes**  
**Participate in two in-person Learning Sessions**  
**Participate in monthly action period webinar/calls (six total)**  
**Help disseminate to other chapter champions, chapter leadership and members, best practices and information related to above initiative** |
As Medical Home Chapter Champion of the _____________ Chapter of the American Academy of Pediatrics (AAP), my plan for working on issues related to medical home and asthma, allergy and/or anaphylaxis is as follows (see “ideas for how to be engaged” in Chapter Champions Orientation Guide):

Interest Pathways: Advocacy, Education, Chapter Involvement, or Medical Home.

<table>
<thead>
<tr>
<th>Goal: Keep this simple and achievable within the timeframe</th>
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<tbody>
<tr>
<td>Interest Pathway: Choose from options above</td>
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<tr>
<th>Activities</th>
<th>Timeframe</th>
<th>Need/Aim</th>
<th>Expected Outcome</th>
<th>Person/Group Responsible</th>
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<tr>
<td>Define each activity that would lead to achieving the above stated goal on its own row. Include as many activities as necessary by adding rows to the table.</td>
<td>An anticipated time period should be included for each activity.</td>
<td>A need/aim for the proposed activity must be defined.</td>
<td>An expected outcome must be defined for each activity.</td>
<td>A responsible person/group must be identified for each activity.</td>
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| Goal: |
| Interest Pathway: |

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Goal: *Keep this simple and achievable within the timeframe*

**Interest Pathway**: *Choose from options above*

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Overall, what specific thing(s) do you want to gain from serving as a chapter champion?

________________________________________
Signature

________________________________________
Date

Submit via e-mail to:
Nkem Chineme, MPH, Program Manager, at nchineme@aap.org.
Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis

2014 Chapter Champions

Alabama
Andrew Wesley Stubblefield, MD, FAAP

Alaska
Melinda Rathkopf, MD, FAAP

Arizona
Lilia Parra-Roide, MD, FAAP

Arkansas
D. Melissa Graham, MD, FAAP

California 1
Dayna Long, MD, FAAP

California 2
Shannon Thyne, MD, FAAP

California 3
Susan Laubach, MD, FAAP

California 4
Christina Schwindt, MD, FAAP

Colorado
Monica Federico, MD, FAAP

Connecticut
Michelle Cloutier, MD

Delaware
Katherine King, MD, FAAP

District of Columbia
Rhonique Harris, MD, MHA, FAAP

Florida
Okan Elidemir, MD, FAAP

Georgia
Dixie Griffin, MD, FAAP

Hawaii
Brian Wu, MD, FAAP

Idaho
David Parry, MD, FAAP

Illinois
Aaron Donnell, MD, FAAP
Ruchi Gupta, MD, FAAP

Indiana
Mary McAteer, MD, FAAP

Iowa
Richard Robus, MD, FAAP

Kansas
Jennifer Mellick, MD, FAAP
Derek Brown, MD, FAAP

Kentucky
Julia Richerson, MD, FAAP

Louisiana
Megan E. Gardner, MD, FAAP

Maine
Christopher Pezzullo, DO, FAAP

Maryland
Virginia Keane, MD, FAAP

Massachusetts
Matthew Sadof, MD, FAAP

Michigan
Harvey Leo, MD, FAAP

Minnesota
*no champion assigned, to date*
Mississippi
Theodore Atkinson, III, MD, FAAP

Missouri
Claudia Preuschoff, MD, FAAP

Montana
*no champion assigned, to date

Nebraska
Stephen Russell, MD, FAAP

Nevada
*no champion assigned, to date

New Hampshire
L. Terry Spencer, Jr., MD

New Jersey
Janice Lichtenberger, MD, FAAP

New Mexico
Kristina Gutierrez-Barela, MD

New York 1
Michael Terranova, MD, FAAP

New York 2
Richard Ancona, MD, FAAP

New York 3
Sankaran Krishnan, MD, MPH, FAAP
Adriana Matiz, MD, FAAP

North Carolina
*no champion assigned, to date

North Dakota
Joan M. Connell, MD, FAAP

Ohio
P. Cooper White, MD, FAAP

Oklahoma
Nighat Mehti, MD, FAAP

Oregon
*no champion assigned, to date

Pennsylvania
Trude Haecker, MD, FAAP

Puerto Rico
*no champion assigned, to date

Rhode Island
Nico Vehse, MD

South Carolina
C. Michael Bowman, MD, PhD, FAAP

South Dakota
Shannon Hoime, MD, FAAP

Tennessee
Suzanne Berman, MD, FAAP

Texas
Barry Lachman, MD, FAAP

Utah
Richard Farnsworth, MD, FAAP

Vermont
Jill Rinehart, MD, FAAP

Virginia
Helen Ragazzi, MD, FAAP

Washington
Jim Stout, MD, MPH, FAAP

West Virginia
Kevin Maupin, MD

Wisconsin
Todd Mahr, MD, FAAP

Wyoming
*no champion assigned, to date

Uniformed Services East
Kermit Helo, MD, MAJ, USAF, MC, FAAP

Uniformed Services West
*no champion assigned, to date
Chairperson
Chuck Norlin, MD, FAAP
Professor of Pediatrics
Adjunct Professor of Biomedical Informatics
University of Utah School of Medicine
Director, Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ)

Members
Julie Katkin, MD, FAAP
Associate Professor of Pediatrics
Texas Children’s Hospital, Clinical Care Center
6621 Fannin Street
Houston, TX 77030

Adriana Matiz, MD, FAAP
Assistant Professor of Pediatrics at CUMC
Medical Director Washington Heights Family Health Center
Medical Director WIN for Asthma
622 West 168th Street VC 4-417
New York, NY 10032

Michael Pistiner, MD, MMSc, FAAP
Pediatric Allergist
Harvard Vanguard Medical Associates
133 Brookline Ave, Boston, MA 02215

Matthew Sadof, MD, FAAP
Associate Professor of Pediatrics
Tufts University School of Medicine
Baystate Children’s Hospital
140 High St
Springfield, MA 01199-1006

Jim Stout, MD, MPH, FAAP
Professor, Department of Pediatrics
University of Washington
6200 NE 74th St, Suite 110
Seattle, WA 98115-8160

David Stukus, MD, FAAP, FAAAAI
Assistant Professor of Pediatrics
Section of Allergy and Immunology
Nationwide Children’s Hospital
700 Children’s Drive, Columbus Ohio 43205

Parent Representative
Michele Carrick, MSW, LICSW
Chair Emeritus, Asthma and Allergy Foundation of America
36 Woburn St
Reading, MA 01867

Liaison
Marie Mann, MD, MPH, FAAP
Integrated Services Branch
DSCSHN/MCHB/HRSA/HHS
5600 Fishers Lane, 13-103
Rockville, MD 20857

Staff
Michelle Esquivel, MPH
Director, Division of Children with Special Needs
Director, National Center for Medical Home Implementation
Phone: 847/434-4989
E-mail: mesquivel@aap.org

Dana Bright, MSW, LSW
Manager
Division of Children with Special Needs
Phone: 847/434-7784
E-mail: dbright@aap.org

Nkem Chineme, MPH*
Program Manager
Division of Children with Special Needs
E-mail: nchineme@aap.org
American Academy of Pediatrics
141 Northwest Point Boulevard
Elk Grove Village, IL 60007
FAX: 847/434-8000
*Primary AAP contact
Chairperson
David Stukus, MD, FAAP, FAAAAI
Assistant Professor of Pediatrics
Section of Allergy and Immunology
Nationwide Children's Hospital
700 Children's Drive, Columbus Ohio
43205

Members
Linda M. Follenweider, MS, PhDc, CNP
Senior Consultant
Health Management Associates
180 North LaSalle, Suite 2305
Chicago, IL 60601

Kimberly Giuliani, MD, FAAP
Staff Physician
Department of General Pediatrics at
Cleveland Clinic
9500 Euclid Avenue
Cleveland, OH 44195

William Long, MD, FAAP
Staff Physician and Medical Director
Pediatric Associates, Inc.
Associate Administrative Medical Director
Nationwide Children’s Hospital
700 Children’s Drive
Columbus, OH 43205

Chuck Norlin, MD, FAAP
Professor of Pediatrics
Adjunct Professor of Biomedical Informatics
University of Utah School of Medicine
Director, Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ)
P.O. Box 581289
Salt Lake City, UT 84158

Parent Representative
Maureen Damitz, AE-C
Program Manager
Pulmonary/Critical Care Division
John H. Stroger Hospital of Cook County
1900 W. Polk St. 14th Floor
Chicago, Illinois 60612

Quality Improvement Advisor
Ruth Gubernick, MPH, PCMH CCE
Independent Consultant/QI Advisor

Staff
Michelle Esquivel, MPH
Director, Division of Children with Special Needs
Director, National Center for Medical Home Implementation
Phone: 847/434-4989
E-mail: mesquivel@aap.org

Dana Bright, MSW, LSW
Manager
Division of Children with Special Needs
Phone: 847/434-7784
E-mail: dbright@aap.org

Nkem Chineme, MPH*
Program Manager
Division of Children with Special Needs
Phone: 847/434-4342
E-mail: nchineme@aap.org

American Academy of Pediatrics
141 Northwest Point Boulevard
Elk Grove Village, IL 60007
FAX: 847/434-8000

*Primary AAP contact
## Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis PAC

**Member District/Chapter Assignments**

### District I & III

<table>
<thead>
<tr>
<th>Champion</th>
<th>Chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michelle M. Cloutier, MD, FAAP</td>
<td>Connecticut</td>
</tr>
<tr>
<td>Rhonique Harris, MD, MHA, FAAP</td>
<td>District of Columbia</td>
</tr>
<tr>
<td>Katherine King, MD, FAAP</td>
<td>Delaware</td>
</tr>
<tr>
<td>Matt Sadof, MD, FAAP</td>
<td>Massachusetts</td>
</tr>
<tr>
<td>Virginia Keane, MD, FAAP</td>
<td>Maryland</td>
</tr>
<tr>
<td>Christopher Pezzullo, DO, FAAP</td>
<td>Maine</td>
</tr>
<tr>
<td>L. Terry Spencer, MD</td>
<td>New Hampshire</td>
</tr>
<tr>
<td>Janice Lichtenberger, MA, FAAP</td>
<td>New Jersey</td>
</tr>
<tr>
<td>Trude Haeker, MD, FAAP</td>
<td>Pennsylvania</td>
</tr>
<tr>
<td>Kermit Helo, MD, FAAP</td>
<td>Rhode Island</td>
</tr>
<tr>
<td>Jill Rinehart, MD, FAAP</td>
<td>Unif. Svcs East</td>
</tr>
<tr>
<td>Kevin Maupin, MD, FAAP</td>
<td>West Virginia</td>
</tr>
</tbody>
</table>

### District VII & X

<table>
<thead>
<tr>
<th>Champion</th>
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</tr>
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<tbody>
<tr>
<td>Andrew Stubblefield, MD, FAAP</td>
<td>Alabama</td>
</tr>
<tr>
<td>D. Melissa Graham, MD, FAAP</td>
<td>Arkansas</td>
</tr>
<tr>
<td>Okan Elidemir, MD, FAAP</td>
<td>Florida</td>
</tr>
<tr>
<td>Dixie Griffin, MD, FAAP</td>
<td>Georgia</td>
</tr>
<tr>
<td>Megan E. Gardner, MD, FAAP</td>
<td>Louisiana</td>
</tr>
<tr>
<td>Theodore Atkinson, MD, FAAP</td>
<td>Mississippi</td>
</tr>
<tr>
<td>Nighat Mehdi, MD, FAAP</td>
<td>Oklahoma</td>
</tr>
<tr>
<td>-</td>
<td>Puerto Rico</td>
</tr>
<tr>
<td>Barry Lachman, MD, FAAP</td>
<td>Texas</td>
</tr>
</tbody>
</table>

### District II & IV

<table>
<thead>
<tr>
<th>Champion</th>
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<tbody>
<tr>
<td>Julia Richerson, MD, FAAP</td>
<td>Kentucky</td>
</tr>
<tr>
<td>-</td>
<td>North Carolina</td>
</tr>
<tr>
<td>Michael Terranova, MD, FAAP</td>
<td>New York 1</td>
</tr>
<tr>
<td>Richard Ancona, MD, FAAP</td>
<td>New York 2</td>
</tr>
<tr>
<td>Sankaran Krishnan, MD, FAAP</td>
<td>New York 3</td>
</tr>
<tr>
<td>Adriana Matiz, MD, FAAP</td>
<td></td>
</tr>
<tr>
<td>C. Michael Bowman, MD, PhD, FAAP</td>
<td>South Carolina</td>
</tr>
<tr>
<td>Suzanne K. Berman, MD, FAAP</td>
<td>Tennessee</td>
</tr>
<tr>
<td>Helen Ragazzi, MD, FAAP</td>
<td>Virginia</td>
</tr>
</tbody>
</table>

### District V & VI

<table>
<thead>
<tr>
<th>Champion</th>
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<tbody>
<tr>
<td>Aaron Donnell, MD, FAAP</td>
<td>Illinois</td>
</tr>
<tr>
<td>Ruchi Gupta, MD, FAAP</td>
<td></td>
</tr>
<tr>
<td>Mary McAttee, MD, FAAP</td>
<td>Indiana</td>
</tr>
<tr>
<td>Richard Robus, MD, FAAP</td>
<td>Iowa</td>
</tr>
<tr>
<td>Jennifer Mellick, MD, FAAP</td>
<td>Kansas</td>
</tr>
<tr>
<td>Harvey Leo, MD, FAAP</td>
<td>Michigan</td>
</tr>
<tr>
<td>-</td>
<td>Minnesota</td>
</tr>
<tr>
<td>Claudia Preuschoff, MD, FAAP</td>
<td>Missouri</td>
</tr>
<tr>
<td>Stephen Russell, MD, FAAP</td>
<td>Nebraska</td>
</tr>
<tr>
<td>Joan M. Connell, MD, FAAP</td>
<td>North Dakota</td>
</tr>
<tr>
<td>P. Cooper White, MD, FAAP</td>
<td>Ohio</td>
</tr>
<tr>
<td>Shannon Hoime, MD, FAAP</td>
<td>South Dakota</td>
</tr>
<tr>
<td>Todd Mahr, MD, FAAP</td>
<td>Wisconsin</td>
</tr>
</tbody>
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### District VIII

<table>
<thead>
<tr>
<th>Champion</th>
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</thead>
<tbody>
<tr>
<td>Melinda Rathkopf, MD, FAAP</td>
<td>Alaska</td>
</tr>
<tr>
<td>Lilia Parra-Roide, MD, FAAP</td>
<td>Arizona</td>
</tr>
<tr>
<td>Monica Federico, MD, FAAP</td>
<td>Colorado</td>
</tr>
<tr>
<td>Brian Wu, MD, FAAP</td>
<td>Hawaii</td>
</tr>
<tr>
<td>David Parry, MD, FAAP</td>
<td>Idaho</td>
</tr>
<tr>
<td>-</td>
<td>Montana</td>
</tr>
<tr>
<td>-</td>
<td>Nevada</td>
</tr>
<tr>
<td>Kristina Gutierrez-Barela, MD</td>
<td>New Mexico</td>
</tr>
<tr>
<td>-</td>
<td>Oregon</td>
</tr>
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<td>Unif. Svcs West</td>
</tr>
<tr>
<td>Richard Farnsworth, MD, FAAP</td>
<td>Utah</td>
</tr>
<tr>
<td>Jim Stout, MD, MPH, FAAP</td>
<td>Washington</td>
</tr>
<tr>
<td>-</td>
<td>Wyoming</td>
</tr>
</tbody>
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### District IX

<table>
<thead>
<tr>
<th>Champion</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Dayna Long, MD, FAAP</td>
<td>California 1</td>
</tr>
<tr>
<td>Shannon Thyne, MD, FAAP</td>
<td>California 2</td>
</tr>
<tr>
<td>Susan Laubach, MD, FAAP</td>
<td>California 3</td>
</tr>
<tr>
<td>Christina Schwindt, MD, FAAP</td>
<td>California 4</td>
</tr>
</tbody>
</table>

* Indicates a PAC member covering a district that is not member's home district.
Allergy & Asthma Network (AAN) is the leading nonprofit family health organization whose mission is to eliminate unnecessary suffering and death due to asthma, allergies and related conditions through education, advocacy and outreach. AAN specializes in sharing family-friendly, medically accurate information through its award-winning publication Allergy & Asthma Today magazine, E-newsletter, website at http://www.aanma.org and numerous community outreach programs.

Nancy Sander founded the organization in 1985 to help families affected by asthma and allergies. She spent years struggling to manage her daughter’s severe symptoms and wanted to help others going through the same thing. Today, AAN’s core areas of expertise are education, advocacy and community outreach. From diagnosis to control, from diapers to college — AAN is your one-stop, family-to-family support network.

**Education:** The AAN website, www.aanma.org, Allergy & Asthma Today magazine and monthly e-newsletter are consumer lifelines to medical news and healthy living. AAN provides families with practical resources they can use at home and in the medical care setting to end suffering and death and reduce costs associated with recurrent symptoms.

**Advocacy:** It’s not only possible to promote financially responsible asthma treatment plans and eliminate asthma deaths – it’s long overdue. AAN has a history of success implementing practical, family-friendly change. Our annual Asthma Awareness Day Capitol Hill highlights critical issues that need national attention. Most recently, we led the campaign to ensure students’ rights to carry and self-administer their lifesaving asthma and anaphylaxis medications at school. Other issues include educating patients and medical professionals about the change from CFC to HFA inhalers and reducing government waste and protecting patients by halting CMS reimbursement for illegally manufactured nebulizer medications.

**Outreach:** AAN volunteers across the country work in their local neighborhoods to serve community needs. Our Hispanic Outreach Program includes culturally competent Spanish-language materials and a volunteer network that works directly with underserved families. Our work is always patient-centered, never endorses products or services and is often available for free.

AAN is your resource for patient-friendly allergy and asthma information. We’re helping America breathe easier . . . one family at a time.

Follow AAN on Facebook at facebook.com/AANMA and on Twitter at twitter.com/AANMA. Join AAN at http://www.aanma.org/join.
Section 2
AAP Chapters
Academy chapters are organized groups of pediatricians and other health care professionals working to achieve AAP goals in their communities. There are 59 chapters in the United States and 7 chapters in Canada. The US chapters generally are drawn along state lines, but two states with large populations (New York and California) constitute more than one chapter. In addition, two chapters serve pediatricians in the uniformed services (east and west, divided by the Mississippi River) and Puerto Rico and the District of Columbia are also separate chapters.

The following is a short listing of AAP chapter facts and figures:

- 66 chapters (59 US, 7 Canadian)
- independently incorporated
- focus on local and state advocacy, education, leadership and networking
- each chapter is governed by its own board/executive board
- 55 chapters and 2 districts have executive directors
- chapter annual operating budgets range from $3,000 to $3,000,000
- number of voting fellows in chapters range from 15 to 2,400
- 59 chapters have secured their own tax-exempt status
- chapter dues range from $0 to $205 depending on member category

Requirements and Autonomy of Chapters
The Academy and its chapters have a unique partnership of autonomy and cooperation. While they are required to maintain bylaws and see that these bylaws do not conflict with the Academy’s bylaws, and are required to elect officers (president and vice president) that are voting members of the national Academy, chapters have complete organizational control over their activities. This autonomy gives chapters the freedom to address the needs and interests of their individual members.

Chapter Representation within the AAP
Chapters are the channels of representation for individual members of the Academy. Annually, two elected leaders from each chapter (usually the president and vice president) are invited to attend the Annual Leadership Forum (ALF). The ALF has become the arena in which the chapter representatives communicate the concerns of the grassroots membership to the Academy leadership. The chapters constitute 10 regional districts of the Academy and individual district meetings are held annually.

The Division of Chapter and District Relations
The Division of Chapter and District Relations provides technical assistance and administrative services to the Academy’s 66 chapters. The division serves as the main liaison between the national office and individual chapters and districts of the Academy on chapter issues. Division staff manage the Annual Leadership Forum, district meetings, and chapter executive director conferences. The division also offers technical assistance to AAP chapters on a number of chapter organizational and structural issues.

To contact the Division of Chapter and District Relations, call 800-433-9016 extension 7949.
### 2014 AAP Chapter Presidents

| Alabama Chapter | Michael J. Ramsey MD, FAAP  
| Dothen Pediatric Clinic  
| 126 Clinic Dr  
| Dothan, AL 36303-1980  
| (334)793-1881 (Phone)  
| (334)712-1815 (Fax)  
| mj_ramsey@msn.com  |
| California Chapter 4 | Angela S. Watson Dangvu MD, FAAP  
| 5 Darwin  
| Irvine, CA 92620-2522  
| (714)544-5513 (Phone)  
| (714)565-7982 (Fax)  
| adangvu@sbglobal.net  |
| Alaska Chapter | Lily Joan Lou, MD, FAAP  
| Alaska Neonatology Associates  
| 3340 Providence Dr Ste A-366  
| Anchorage, AK 99508-4691  
| (907)212-6810 (Phone)  
| (907)212-8453 (Fax)  
| lilylou@mindspring.com  |
| Arizona Chapter | Delphis Coleman Richardson, MD, FAAP  
| Mesa Pediatrics  
| Attn Sara Oliver  
| 6301 S McClintock Dr Ste 101  
| Tempe, AZ 85283-3393  
| (480) 831-6800 (Phone)  
| (480) 897-2799 (Fax)  
| delphis.richardson@gmail.com  |
| Arkansas Chapter | Orrin J. Davis, MD, FAAP  
| Northwest Arkansas Pediatric Clinic  
| 3380 N Futrall Dr Ste 1  
| Fayetteville, AR 72703-4815  
| (479) 445-9965 (Phone)  
| orrin.davis@mana.md  |
| California Chapter 1 | Gena Lee Lewis, MD, FAAP  
| 5220 Claremont Avenue  
| Oakland, CA 94618-1033  
| (510) 893-0322 (2621) (Phone)  
| glewis@mail.cho.org  |
| California Chapter 2 | Paula Jo Whiteman MD, FACEP, FAAP  
| Cedars Sinai Medical Center  
| Staff  
| Dept of Emergency Medicine  
| 8700 Beverly Blvd  
| West Hollywood, CA 90048-1804  
| (310) 423-8780 (Phone)  
| (818) 766-0117 (Fax)  
| pjwhiteman@aap.net  |
| California Chapter 3 | Wendy K. Wright, MD, FAAP  
| Pediatrics / MC 5064  
| 3020 Children's Way  |
| San Diego, CA 92123-4223  
| (858)966-5841 (Phone)  
| (858)966-6728 (Fax)  
| wwright@rchsd.org  |
| Colorado Chapter | Joseph Allan Craig, MD, FAAP  
| Kaiser Ken Caryl Clinic  
| Dept of Pediatrics  
| 7600 Shaffer Pkwy  
| Littleton, CO 80127-3004  
| (720)203-2442 (Phone)  
| (720)922-5245 (Fax)  
| joe.craig@ucdenver.edu  |
| Connecticut Chapter | Sandra Lee Carbonari, MD, FAAP  
| 77 North Farm Rd  
| Middlebury, CT 06762-1414  
| (203)598-5522 (Phone)  
| (203)573-1875 (Fax)  
| sandiwelsh12@gmail.com  |
| Delaware Chapter | Mary L. Gavin, MD, FAAP  
| 240 Dogwood Ln  
| Berwyn, PA 19312-1737  
| (302)507-2323 (Phone)  
| mgavin@nemours.org  |
| District of Columbia Chapter | Olanrewaju Omojokun Falusi, MD, FAAP  
| 1 Morning Breeze Ct  
| Silver Spring, MD 20904-1248  
| (703) 600-9432 (Phone)  
| Lanro@alumni.virginia.edu  |
| Florida Chapter | Tommy Jay Schechtman, MD, FAAP  
| 3401 PGA Blvd Suite 300  
| Palm Beach Gardens, FL 33410-2824  
| (561)745-4224 (Phone)  
| tschechtman@pediatricpartners.com  |
| Georgia Chapter | Evelyn D. Johnson, MD, FAAP  
| 1600 Gloucester St  
| Brunswick, GA 31520-7145  |
| Hawaii Chapter | R. Michael Hamilton, MD, FAAP  
| Pediatrics  
| Kaiser Permanente Mapunapuna Clinic  
| 2828 Paa St Pediatrics 2nd Flr  
| Honolulu, HI 96819  
| (808)432-5656 (Phone)  
| michael.r.hamilton@kp.org  |
| Idaho Chapter | Scott Alan Snyder, MD, FAAP  
| 425 W O’Farrell St  
| Boise, ID 83702-4428  
| (208)381-2088 (Phone)  
| (208)381-2893 (Fax)  
| snyders@slhs.org  |
| Illinois Chapter | Barbara Wood Bayldon, MD FAAP  
| Ann & Robert H Lurie Children Hospital of Chicago  
| 225 E Chicago Ave Box 16  
| Chicago, IL 60611-2991  
| (312) 227-6110 (Phone)  
| bbayldon@luriechildrens.org  |
| Indiana Chapter | Nancy Lynn Swigonski, MD, MPH, FAAP  
| Riley Hospital for Children  
| Children’s Health SVCS Resrch  
| 410 West 10th St Suite 1020  
| Indianapolis, IN 46202-3011  
| (317) 278-0552 (Phone)  
| (317) 278-0456 (Fax)  
| nswigons@iuuiui.edu  |
| Iowa Chapter | Jennifer Ann Groos, MD, FAAP  
| 6806 61st Ln  
| Norwalk, IA 50211-9415  
| (515)241-6000 (Phone)  
| (515)241-8728 (Fax)  
| jagiowa@yahoo.com  |
| Kansas Chapter | Robert Richard Wittler, MD, FAAP  
| Dept of Pediatrics  
| 3243 E Murdoch St Ste 402  
| Wichita, KS 67208-3007  
| (316)962-2080 (Phone)  
| (316)962-2079 (Fax)  
| rwittler@kumc.edu  |

10/14/2014
Kentucky Chapter
Kimberly Anne Boland, MD, FAAP
211 S Peterson Ave
Louisville, KY 40206-2538
(502)626-8828 (Phone)
(502)626-6783 (Fax)
k.boland@louisville.edu

Missouri Chapter
Sandra Lynn McKay, MD FAAP
Mercy Clinic Pediatrics
2223 Technology Dr Suite 10
O Fallon, MO 63368-7272
(636)240-9896 (Phone)
sandra.mckay@mercy.net

Montana Chapter
Pepper J. Henyon, MD, FAAP
3213 Augusta Dr
Bozeman, MT 59715-8792
(406)587-5827 (Phone)
(406)586-8591 (Fax)
pepperhenyon@gmail.com

Nebraska Chapter
Jane Marie Carnazzo, MD, FAAP
Children’s Physicians, Spring Valley
4224 S 50th St
Omaha, NE 68117-1332
(402)855-7474 (Phone)
(402)855-7476 (Fax)
jmcarnazzo@cox.net

New Hampshire Chapter
William Robert Storo, MD, FAAP
Dartmouth Hitchcock Clinic Staff
253 Pleasant St
Concord, NH 03301-7560
(603)229-5150 (Phone)
(603)229-5314 (Fax)
billstoro@gmail.com

New Jersey Chapter
Elliot H. Rubin, MD, FAAP
51 So Adelaide Ave
Highland Park, NJ 08904-1601
(732)236-2850 (Phone)
(732)289-6206 (Fax)
ehrubin@aap.net

New Mexico Chapter
Alexandra Jasmina Cvijanovich, MD, FAAP
3924 Silver Ave SE
Albuquerque, NM 87108-2642
(505)823-8288 (Phone)

New York Chapter 1
Eric L. Beyer, MD, FAAP
Canandaigua Medical Group
335 Parrish St
Canandaigua, NY 14424-1728
(585)393-2860 (Phone)
(585)393-1789 (Fax)
eric@beyer.bz

New York Chapter 2
Marc Lashley, MD, FAAP
Valley Stream Pediatrics
167 E Merrick Road
Valley Stream, NY 11580-5925
(516)825-3030 (Phone)
(516)825-4282 (Fax)
vspeds@optonline.net

New York Chapter 3
Maida P. Galvez, MD, MPH, FAAP
Depts of Preventive Medicine and Pediatrics
Icahn SCHL of Med at Mt Sinai
One Gustave L Levy Pl Box 1057
New York, NY 10029-0310
(212)824-7148 (Phone)
(212)824-3331 (Fax)
maida.galvez@mssm.edu

North Carolina Chapter
Deborah Lowry Ainsworth, MD, FAAP
Washington Pediatrics
1206 Brown St
Washington, NC 27889-4671
(252)946-4134 (Phone)
(252)946-2432 (Fax)
drains@suddenlink.net

North Dakota Chapter
Joan Marie Connell, MD, FAAP
402 West Avenue B
Bismarck, ND 58501-3414
(701)425-2067 (Phone)
(701)530-6469 (Fax)
jmconnellmd@msn.com

Ohio Chapter
Andrew S. Garner, MD, PhD, FAAP
960 Clague Rd Ste 1850
Westlake, OH 44145-7705
(440)808-9228 (Phone)
(440)808-9234 (Fax)
andrew.garner@UHhospitals.org

Oklahoma Chapter
Eve Hsing Switzer, MD, FAAP
Northwest Pediatrics
3201 N Van Buren St Ste 300
Enid, OK 73703-1800
(580)234-7070 (Phone)

10/14/2014
Texas Chapter
Oscar ‘Skip’ Wharton Brown III, MD, FAAP
3506 Foremast Dr
Galveston, TX 77554-6292
(409)772-3303 (Phone)
(409)747-4995 (Fax)
owbrown@utmb.edu

Uniformed Services-East
Chapter
Lt Col Eric Melvin Flake, MD
1923 Nelson St
DuPont, WA 98327-7743
(253)227-4614 (Phone)
lonofile@us.af.mil

Uniformed Services-West
Chapter
LTC Keith M. Lemmon MD, FAAP
1268 O’Neil Ct
DuPont, WA 98327-9764
(253)920-1325 (Phone)
(253)968-0384 (Fax)
kleemmon2@gmail.com

Utah Chapter
William E. Cosgrove, MD, FAAP
5770 S 250 East #290
Murray, UT 84107-6146
(801)553-6175 (Phone)
(801)747-8701 (Fax)
wecosgrove@yahoo.com

Vermont Chapter
Barbara Louise Frankowski, MD, MPH, FAAP
156 Skunk Hollow Road
Jericho, VT 05455-3033
(802)847-4696 (Phone)
(802)847-4612 (Fax)
barbara.frankowski@vtmednet.org

Virginia Chapter
Barbara Lyons Kahler, MD, FAAP
156 Bayberry Ln
Lancaster, VA 22503-2337
(804)435-1152 (Phone)
(804)435-8080 (Fax)
blkahler@msn.com

Washington Chapter
Margaret Elizabeth Hood, MD, FAAP
9209 49th Ave NE
Seattle, WA 98115-3903
(206)905-1816 (Phone)
Maggie.hood@hotmail.com

West Virginia Chapter
Raheel R. Khan, MD, FAAP
WVU/Charleston Area Medical
Center/Peds
Program Director
830 Pennsylvania Ave Ste 104
Charleston, WV 25302-3389
(304)388-1549 (Phone)
(304)388-1577 (Fax)
raheel.khan@camc.org

Wisconsin Chapter
Jeffrey W. Britton, MD, FAAP
Aurora Sheboygan Clinic Pediatrics
2414 Kohler Memorial Dr
Sheboygan, WI 53081-3129
(920)457-4461 (Phone)
(920)459-1170 (Fax)
jeffrey.w.britton@aurora.org

Wyoming Chapter
Brian Paul Horst, MD, FAAP
3115 Hayford Ave
Laramie, WY 82072-5080
(307)721-3118 (Phone)
(307)721-4880 (Fax)
brianhorst@bresnan.net

Oregon Chapter
Gregory S. Blaschke, MD, MPH, FAAP
Associate Professor
Division Head, General Pediatrics
707 SW Gaines Street CDRC-P
Portland, OR 97239
(503)720-7568 (Phone)
blaschke@ohsu.edu

Pennsylvania Chapter
Susan Jane Kressly, MD, FAAP
Kressly Pediatrics PC
1432 Easton Rd Suite 4E
Warrington, PA 18976-2852
(215)343-5220 (Phone)
(215)343-5521 (Fax)
skressly@kresslypediatrics.com

Puerto Rico Chapter
Ricardo M. Fontanet, MD, FAAP
Centro Pediatrico Country Club
Staff
G07 Cntr CLB Ave Roberto Sanch
Carolina, PR 00982
(787)769-4079 (Phone)
(787)762-9110 (Fax)
rfontanet@hotmail.com

Rhode Island Chapter
Ailis Clyne, MD, FAAP
40 Bellewood Ct
North Kingstown, RI 02852-5308
(401)615-2299 (Phone)
ailisc@yahoo.com

South Carolina Chapter
J. Routt Reigart, MD, FAAP
812 Harbour Watch Ct
Mount Pleasant, SC 29464-2860
(843)876-8512 (Phone)
(843)876-8709 (Fax)
reigart@musc.edu

South Dakota Chapter
Joseph Alexander Zenel Jr, MD, FAAP
5105 S Barrington Dr
Sioux Falls, SD 57108-5000
(605)333-7181 (Phone)
(605)333-7198 (Fax)
Joe.Zenel@sanfordhealth.org

Tennessee Chapter
Michelle Dorothy Fiscus, MD, FAAP
508 Autumn Springs Ct Suite 2B
Franklin, TN 37067-8273
(615)599-1727 (Phone)
(615)261-5445 (Fax)
shelley.fiscus@tnaap.org

West Virginia Chapter
Raheel R. Khan, MD, FAAP
WVU/Charleston Area Medical
Center/Peds
Program Director
830 Pennsylvania Ave Ste 104
Charleston, WV 25302-3389
(304)388-1549 (Phone)
(304)388-1577 (Fax)
raheel.khan@camc.org

Wisconsin Chapter
Jeffrey W. Britton, MD, FAAP
Aurora Sheboygan Clinic Pediatrics
2414 Kohler Memorial Dr
Sheboygan, WI 53081-3129
(920)457-4461 (Phone)
(920)459-1170 (Fax)
jeffrey.w.britton@aurora.org

Wyoming Chapter
Brian Paul Horst, MD, FAAP
3115 Hayford Ave
Laramie, WY 82072-5080
(307)721-3118 (Phone)
(307)721-4880 (Fax)
brianhorst@bresnan.net

10/14/2014
Alabama Chapter
Catherine L. Wood MD FAAP
8160 Seaton Pl
Montgomery, AL 36116-7204
(334)565-4220 (Phone)
(334)272-4876 (Fax)
cdocwood@aol.com

Alaska Chapter
Rachel Mauryce Kerford Lescher
MD FAAP
3370 Cosmic Circle
Anchorage, AK 99517-1636
(907)230-7424 (Phone)
rachelklescher@gmail.com

Arizona Chapter
John Anthony Pope MD MPH
FAAP
10450 E Shangri La Rd
Scottsdale, AZ 85259-6540
(480)323-3510 (Fax)
azjp63@gmail.com

Arkansas Chapter
Dennis Zane Kuo MD MHS FAAP
315 Linwood Ct
Little Rock, AR 72205-4244
(201)220-9665 (Phone)
dzkuo@uams.edu

California Chapter 1
Zoey Jayne Goore MD FAAP
4725 Lake Dr
Carmichael, CA 95608-3137
(916)358-0178 (Phone)
(916)787-6450 (Fax)
zgoore@gmail.com

California Chapter 2
Edward S. Curry MD FAAP
Kaiser Permanente
9985 Sierra Ave
Fontana, CA 92335-6720
(909)496-5325 (Phone)
(909)427-4857 (Fax)
edward.s.curry@kp.org

California Chapter 3
Patricia E Cantrell MD FAAP
9819 Caminito Rogelio
San Diego, CA 92131-2124
(619)244-1593 (Phone)
drpatacantrell@gmail.com

California Chapter 4
Dean Stuart Jacobs MD FAAP
Pediatrics Primary Care Clinic
455 South Main Street
Orange, CA 92868-3835
(714)509-8767 (Phone)
(714)509-4551 (Fax)
dr4kids@gmail.com

Colorado Chapter
Steven S Perry MD FAAP
978 S High St
Denver, CO 80209-4551
(303)756-9897 (Fax)
sperry7893@msn.com

Connecticut Chapter
Anton M. Alerte MD FAAP
131 Coventry St
Hartford, CT 06112-1548
(860)983-9292 (Phone)
(860)714-8997 (Fax)
aalerte2ccmc@yahoo.com

Delaware Chapter
Amanda J. Kay MD FAAP
Dept of Pediatrics / Rm 4A30
501 West 14th Street
Wilmington, DE 19801-1013
(302)530-4648 (Phone)
AKay@Christianacare.org

District of Columbia Chapter
Mark D Minier MD FAAP
Upper Cardozo Health Center
3020 14th St NW
Washington, DC 20009-6865
(202)530-2374 (Phone)
mminier@unityhealthcare.org

Florida Chapter
Madeline Matar Joseph MD FAAP
700 Queens Harbour Blvd
Jacksonville, FL 32225-4901
(904)244-4124 (Phone)
(904)244-4508 (Fax)
madeline.joseph@jax.ufl.edu

Georgia Chapter
Benjamin David Spitalnick MD FAAP
4600 Waters Ave Suite 100
Savannah, GA 31404-6274
(912)398-1971 (Phone)
(912)353-1836 (Fax)
Bspitalnick@pedsav.com

Hawaii Chapter
Mae S.I. Kyono MD FAAP
105 Dowsett Ave
Honolulu, HI 96817-1109
(808)595-0476 (Phone)
mkyono@hawaii.edu

Idaho Chapter
Jean Marie Prince MD FAAP
3488 Spinnaker Way
Coeur D Alene, ID 83814-9548
(208)292-5437 (Phone)
jprince@lakesidedepa.net

Illinois Chapter
Alison Siegel Tothy MD FAAP
5800 S Harper Ave
Chicago, IL 60637-1843
(312)315-0200 (Phone)
atothy@pedsbsd.uchicago.edu

Indiana Chapter
Sarah Spitznagel Bosslet MD FAAP
7610 Dubonnet Way
Indianapolis, IN 46278-1542
(317)246-0856 (Phone)
sbosslet@yahoo.com

Iowa Chapter
Marguerite Henry Oetting MD FAAP
University of Iowa Hospitals & Clinics
Dept of Pediatrics
200 Hawkins Dr
Iowa City, IA 52242-1009
(319)338-7278 (Phone)
mhoetting@mchsi.com

Kansas Chapter
Jennifer R Mellick MD FAAP
7301 W 133rd Street
Overland Park, KS 66213-4750
(913)888-1277 (Fax)
drmellick@doc4kidz.com

Kentucky Chapter
Jeffrey Thomas Grill MD FAAP
7006 White Blossom Blvd
Louisville, KY 40241-4163
jeff.grill@louisville.edu

Louisiana Chapter
John Anthony Vanchiere MD PhD FAAP
Dept of Pediatrics
1501 Kings Highway

10/14/2014
Puerto Rico Chapter
Ines Del Carmen Cuebas Rolon MD FAAP
Mansiones De Monte Verde
Cayey, PR 00736
(787)292-4297 (Fax)
dra_ines_cuebas@yahoo.com

Rhode Island Chapter
Nicole Everline Alexander-Scott MD, MPH FAAP
555 S Main St Apt 231
Providence, RI 02903
(917)696-6998 (Phone)
(401)444-5650 (Fax)
nalexanderscott@lifespan.org

South Carolina Chapter
Kevin O Wessinger MD FAAP
1749 Marshall St
Columbia, SC 29203
(803)463-6552 (Phone)
(803)252-9132 (Fax)
kwessinger@sc.rr.com

South Dakota Chapter
Rick A. Kooima MD FAAP
Avera Medical Group, McGreevy Clinic
1200 S. 7th Av.
Sioux Falls, SD 57105-0900
(605)333-0953 (Phone)
(605)782-8319 (Fax)
ricky.kooima@avera.org

Tennessee Chapter
Helen Gail Beeman MD MHPE FAAP
5660 Gwynne Cv
Memphis, TN 38120-2012
(901)287-4592 (Phone)
(901)287-4478 (Fax)
gbeeman@uthsc.edu

Texas Chapter
Kimberly Cruzita Avila Edwards MD FAAP
12508 Bears Den Ct
Austin, TX 78739-7600
(512)292-8867 (Phone)
kcavilaedwards@arcmd.com

Uniformed Services-East Chapter
Maj. Dalila Watford Lewis MD FAAP
5105 Waterford Pl
Suffolk, VA 23435-3528
(301)741-3572 (Phone)
dwlewismd@yahoo.com

Uniformed Services-West Chapter
MAJ Amy Marie Thompson USA MC DO FAAP
2802 Lakeview Ter
Milford, KS 66514-8399
(253)592-4389 (Phone)
thompsonamy77@gmail.com

Utah Chapter
Charles Pruitt MD FAAP
Pediatrics
Pediatric Emergency Medicine
PO Box 581289
Salt Lake City, UT 84158-1289
(801)587-7305 (Phone)
(801)587-7455 (Fax)
charles.pruitt@hsc.utah.edu

Vermont Chapter
Jill Stuart Rinehart MD FAAP
24 Brewer Pkwy
South Burlington, VT 05403-7325
(802)860-1928 (Phone)
(802)860-0192 (Fax)
doctorjillrinehart@comcast.net

Virginia Chapter
Sam Bartle MD FAAP
2340 Burroughs St
North Chesterfield, VA 23235-3176
(804)512-4163 (Phone)
(804)828-1151 (Fax)
sbartle@mcvh-vcu.edu

Washington Chapter
Michael S. Dudas MD FAAP
Virginia Mason Sand Point Pediatrics
4575 Sand Point Way NE Ste 108
Seattle, WA 98105-3999
(206)525-5000 (Phone)
(206)525-5000 (Fax)
michael.dudas@vmmc.org

West Virginia Chapter
John Robert Phillips MD FAAP
Pediatrics
Pediatric Cardiology
PO Box 9214 Ped Cardiology
Morgantown, WV 26506-9214
(304)293-7036 (Phone)
(304)293-1409 (Fax)
jphillips@hsc.wvu.edu

Wisconsin Chapter
Madhulika Mathur MD MPH FAAP
1321 Redan Drive
Verona, WI 53593-7820
(608)497-0441 (Phone)
mmathur1321@gmail.com

Wyoming Chapter
Debra M Anderson MD FAAP
2710 Harney Ste 100
Laramie, WY 82072-0001
(307)721-3118 (Phone)
(307)721-4880 (Fax)
drsanderson@bresnan.net
**2014 AAP CHAPTER EXECUTIVE DIRECTORS**

**Alabama Chapter**
Ms Linda P. Lee APR
19 S Jackson St
Montgomery, AL 36104-3812
(334) 954-2543 (Phone)
(334) 269-5200 (Fax)
llee@aap.net

**Alaska Chapter**
Stephanie Monahan
3012 Redwood Dr
Anchorage, AK 99508-4212
(907)903-6770 (Phone)
stephanie@a2p2.com

**Arizona Chapter**
Sandia Price, JD, PhD
2600 N Central Ave 18th Floor
Phoenix, AZ 85004-3099
(602)532-0137 (Phone)
(602)532-0139 (Fax)
sandy@azaap.org

**Arkansas Chapter**
Aimee Berry
3315 Doral Drive
Little Rock, AR 72212-2901
(501) 831-3057 (Phone)
(501) 364-1561 (Fax)
berryaimee@sbcglobal.net

**California Chapter 1**
Beverly Buscher
68 Mitchell Blvd #252
San Rafael, CA 94903-2048
(415) 479-9200 (Phone)
(415) 479-9202 (Fax)
aapbev@sbcglobal.net

**California Chapter 2**
Tomás Torices, MD
4067 Hardwick St Box 527
Lakewood, CA 90712-2350
(888)838-1987 (Phone)
(888)838-1987 (Fax)
ttorices@aap.com

**California Chapter 3**
Meredith Kennedy MPH
Po Box 22212
San Diego , CA 92192-2212
(619)281-2273 (Phone)
(858)453-1311 (Fax)
mkennedy@aapca3.org

**California Chapter 4**
Letitia Clark George, MPP
17322 Murphy Ave
Irvine, CA 92614-5920
(949)752-2787 (Phone)
(949)752-2788 (Fax)
lclarkgeorge@aapca4.org

**Colorado Chapter**
Carol A Goddard
Po Box 4834
Englewood, CO 80155-4834
(303) 770-6048 (Phone)
(303) 771-2550 (Fax)
carol@goddardassociates.com

**Connecticut Chapter**
Jillian Wood
104 Hungerford St
Hartford CT 06106-4626
(860) 402-1554 (Phone)
(860) 727-9863 (Fax)
jillianwood@sbcglobal.net

**Delaware Chapter**
Katie Hamilton
900 Prudential Crossing
Newark, DE 19713-6100
(302)218-1075 (Phone)
khamilton@deaap.org

**District of Columbia Chapter**
Nancy Schoenfeld, JD
PO Box 6236
Washington, DC 20015-0236
(301)655-4767 (Phone)
(301)279-9330 (Fax)
nancyLSchoenfeld@gmail.com

**Florida Chapter**
Eric Carr
1430 Piedmont Drive East
Tallahassee, FL 32308-7949
(850)224-3939 (Phone)
exec@fcap.com

**Georgia Chapter**
Rick Ward, CAE
1330 W Peachtree St NW Suite 500
Atlanta, GA 30309-2950
(404) 881-5090 (Phone)
(404) 249-9503 (Fax)
rward@gaaap.org

**Hawaii Chapter**
Kathryn Sthay
5414 Kirkwood Place
Honolulu, HI 96821-1938
(808) 377-5738 (Phone)
(808) 377-3683 (Fax)
aaphawaii@hawaiiantel.net

**Idaho Chapter**
Sherry Iverson, RN
6025 Randolph
Boise, ID 83709-2155
(208) 381-3033 (Phone)
(208) 381-4677 (Fax)
iversons@alhs.org

**Illinois Chapter**
Scott Allen, MS
1400 W Hubbard Ste 100
Chicago, IL 60612-8195
(312) 733-1026 (202) (Phone)
(312) 733-1791 (Fax)
sallens@illinoisaap.com

**Indiana Chapter**
Jean M. Caster
PO Box 29275
Indianapolis, IN 46229-0275
(317)586-0732 (Phone)
jcaster@inaap.org

**Iowa Chapter**
Tess Barker, PhD, JD, MA
100 Hawkins Dr-247 CDD
Iowa City, IA 52242-1016
(319)584-4067 (Phone)
(319)356-3715 (Fax)
tess-barker@uiowa.edu

**Kansas Chapter**
Chris Steege
9905 Woodstock St
Lenexa, KS 66220-8000
(913) 780-5649 (Phone)
(866) 519-0365 (Fax)
chris.steege@kansasaap.org

**Kentucky Chapter**
Mary York, MM
3140 Sunny Ln
Louisville, KY 40205-2825
(502)875-2205 (Phone)
(502)227-1721 (Fax)
maryyork@kyaap.org

**Louisiana Chapter**
Ashley Politz, LMSW
Po Box 64629
Baton Rouge, LA 70896-4629
(225) 379-7923 (Phone)
ashley.politz@laaap.org

10/14/2014
Maine Chapter
Dee Kerry deHaas
30 Association Drive PO Box 190
Manchester, ME 04351-0190
dkerry2014@gmail.com

Maryland Chapter
Paula K. Minsk, Med, CFRE
1211 Cathedral Street
Baltimore, MD 21201-5516
(410)878-9702 (Phone)
(410)649-4131 (Fax)
paula@mdaap.org

Massachusetts Chapter
Cathleen Haggerty
Massachusetts Medical Society
860 Winter St
Waltham, MA 02451-1449
(781) 895-9852 (Phone)
(781) 895-9855 (Fax)
chaggerty@mcaap.org

Michigan Chapter
Denise Sloan
106 E Allegan St. Ste 510
Lansing, MI 48933-1706
(517) 484-3013 (Phone)
(517) 371-9080 (Fax)
denise.sloan@minap.org

Minnesota Chapter
Katherine Cairns, MPH, MBA, RD
1043 Grand Ave #544
Saint Paul, MN 55105-3002
(651) 402-2056 (Phone)
(651) 699-7798 (Fax)
cairns@minap.org

Mississippi Chapter
Gretchen Mahan
PO Box 702
Madison, MS 39130-0702
(601)605-6425 (Phone)
(601)605-8367 (Fax)
msaap@integrity.com

Missouri Chapter
Johanna B. Derda
1537 B Cedar Ridge Place
Jefferson City, MO 65109-1909
(573) 301-3468 (Phone)
(573) 893-5393 (Fax)
jbderda@aap.net

Montana Chapter
Molly Taylor, MBA
1540 Trailcrest Dr
Boxeman, MT 59718-9465
(406) 581-6441 (Phone)
mollytaylormtaap@gmail.com

Nebraska Chapter
Jody Hatz, MSW
Po Box 72 Nebraska Chapter AAP
Elkhorn, NE 68022-0072
(402)740-4906 (Phone)

New Hampshire Chapter
Catrina Watson
New Hampshire Pdatr Soc Society
7 N State St
Concord, NH 03301-4039
(603) 224-1909 (Phone)
(603) 226-2432 (Fax)
catrina.watson@nhms.org

New Jersey Chapter
Fran Gallagher MEd
3836 Quakerbridge Rd Ste 108
Hamilton, NJ 08619-1006
(609) 842-0014 (Phone)
(609) 842-0015 (Fax)
fgallagher@aap.net

New Mexico Chapter
Johannah Ruddy, MEd, CMP
8201 Golf Course NW #D3
Albuquerque, NM 87120-5841
(505)962-2207 (Phone)
(505)344-9864 (Fax)
jruddy@nmaap.org

New York Chapter 1
Nancy Adams, MSM
132 Allens Creek Rd
Rochester, NY 14618-3310
(585) 473-4072 (Phone)
(585) 473-7641 (Fax)
nadams@mems.org

New York Chapter 2
Elie Ward, MSW
510 Shaker Museum Rd
Old Chatham, NY 12136-3105
(518)441-4544 (Phone)
eswabc@gmail.com

New York Chapter 3
Elie Ward, MSW
510 Shaker Museum Rd
Old Chatham, NY 12136-3105
(518)441-4544 (Phone)
eswabc@gmail.com

North Carolina Chapter
Elizabeth Hudgins, MMP
1100 Wake Forest Rd #150
Raleigh, NC 27604-1354
(919) 839-1156 (Phone)
elizabeth@ncaap.net

North Dakota Chapter
Kyle Nissen
773 S 83rd St

Ohio Chapter
Melissa Arnold
94-A Northwoods Blvd
Columbus, OH 43235-4721
(614)846-6258 (Phone)
(614)846-4025 (Fax)
marnold@ohioaap.org

Oklahoma Chapter
Amy Prentice
6840 S Trenton Ave
Tulsa, OK 74136-4106
(918) 858-0298 (Phone)
(918) 747-5596 (Fax)
aprentice@upal.com

Oregon Chapter
Crystal A. Milazzo, MPA
Suite 210 Bldg 2
4000 Kruse Way Place
Lake Oswego, OR 97035-5545
(503)334-1591 (Phone)
(503)334-1598 (Fax)
crystal.milazzo@oraap.org

Pennsylvania Chapter
Suzanne Yunghans MMgt
Rose Tree Corporate Center
1400 N Providence Rd Ste 3007
Media, PA 19063-2070
(484) 446-3000 (Phone)
(484) 446-3255 (Fax)
syunghans@paap.org

Puerto Rico Chapter
Ingrid Milagros Marino MD FAAP
PO Box 1573
Dorado, PR 00646-1573
(787)529-3059 (Phone)
(787)796-1024 (Fax)
imarino@libertypr.net

Rhode Island Chapter
Francis A. Donahue, MPA
7 Sweet Corn Dr
Cranston, RI 02921-2021
(401) 228-6441 (Phone)
(401) 228-6441 (Fax)
fdonahue@cox.net

South Carolina Chapter
Debbie Shealy
132 Westpark Blvd
Columbia, SC 29210-3856
(803) 798-6207 (223) (Phone)
(803) 772-6753 (Fax)
debbies@csmedical.org

South Dakota Chapter
Amber Mae Hobert
26447 467th Ave
Sioux Falls, SD 57107-7032

10/14/2014
Tennessee Chapter
Ruth E. Allen
Executive Director, TN AAP
11474 Couch Mill Rd
Knoxville, TN 37931-2937
(865) 927-3030 (Phone)
(865) 927-8039 (Fax)
ruth.allen@tnaap.org

Texas Chapter
Tricia Hall, CAE, CMP
401 W 15th St, Ste 682
Austin, TX 78701-1665
(512) 370-1506 (Phone)
(512) 473-8659 (Fax)
tricia.hall@txpeds.org

Uniformed Services-East Chapter
Carolyn L. Famiglietti
77 Nealy Ave 633D Medical GRP
Hampton, VA 23665-2040
(757)817-0562 (Phone)
carolyn.famiglietti@us.af.mil

Uniformed Services-West Chapter
Elina H Ly
Naval Medical Center San Diego
34800 Bob Wilson Dr
San Diego, CA 92134-0001
(619) 532-5233 (Phone)
(619) 532-5507 (Fax)
Elina.Ly@med.navy.mil

Utah Chapter
Cathy Oyler
Utah Chapter AAP
3029 Holderhill Ln
Taylorsville, UT 84129-2276
(801)968-3411 (Phone)
(801)968-2616 (Fax)
office@aaputah.org

Vermont Chapter
Stephanie Winters
PO Box 1457
Montpelier, VT 05601-1457
(802) 223-7898 (Phone)
(802) 223-1201 (Fax)
swinters@vtmd.org

Virginia Chapter
Jane B Chappell
2821 Emerywood Pkwy
Suite 200
Richmond, VA 23294-3726
(804)622-8135 (Phone)
(804)788-9987 (Fax)
jchappell@ramdocs.org

Washington Chapter
Anne Stone, MA, MPA
4616 25th Ave NE #594
Seattle, WA 98105-4183

(605)333-7197 (Phone)
(605)333-7198 (Fax)
sd_aap_chapter@hotmail.com

West Virginia Chapter
Jeri Whitten C-TAGME
830 Pennsylvania Ave Suite 104
Charleston, WV 25302-3389
(304) 388-1563 (Phone)
(304) 388-2926 (Fax)
jwhitten@hsc.wvu.edu

Wisconsin Chapter
Kia K LaBracke
N66 W38592 North Woodlake Cir
Oconomowoc, WI 53066-1692
(262) 490-9075 (Phone)
KLaBracke@aap.net

Wyoming Chapter
Sheila Bush
Po Box 4009
Cheyenne, WY 82003-4009
(307) 635-2424 (Phone)
(307) 632-1973 (Fax)
sheila@wyomed.org
Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis

Chapter Champion

STEPS FOR COMMUNICATING WITH CHAPTER LEADERSHIP

<table>
<thead>
<tr>
<th>Rationale</th>
<th>Talking Points</th>
</tr>
</thead>
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**Rationale**

Most AAP chapters have very full plates, with many initiatives and strategic priorities. Many chapters have written strategic plans to guide the work of the chapter leadership and staff, helping them stay on course with their priorities. It would be extremely beneficial for chapter champions to get to know the chapter president and executive director to learn about the chapter’s priorities, and to set the stage for work related to asthma and the medical home as part of this project.

**Talking Points**

- Do you know your chapter president and executive director? If not, the first step is to introduce yourself, ideally on the telephone or in person, perhaps at a chapter meeting.

- Ask for a meeting with BOTH the president and the chapter executive director. In your ask you could cite, for example, the importance of the medical home on the national front, especially given payer and governmental influences that are shaping this national conversation.

**Meanwhile, do your homework:**

- Find out if the chapter has a strategic plan. Many chapters post their strategic plans on their chapter web site. A listing of chapter website addresses can be found on the member portion of the AAP web site under Districts/Chapters).

- Use the plan as an opportunity to gain insight into what drives the chapter’s work.

- If there is no written plan, ask the chapter executive director where he/she sees medical home/asthma, allergy and anaphylaxis fitting in with their unwritten priorities.

- If medical home/asthma, allergy and anaphylaxis is part of the chapter’s current priorities, your request for face time will be a much easier sell.

- If they are not part of the plan, be prepared with your talking points about what you can offer the chapter (using the suggested implementation ideas in the Chapter Champions’ Roles, Responsibilities and Implementation Ideas).

- Once at the meeting, begin a discussion on the goals of the Medical Home Chapter Champions Program on Asthma, Allergy and Anaphylaxis and why it is important to your state’s practicing pediatricians and their patients. (Always remember the “what’s in it for me?” question.)

- Be prepared to emphasize the implementation ideas that can make the executive director’s life easier (i.e., canned newsletter articles, etc.)

- Also, be prepared to be flexible with the chapter’s schedules, meetings, deadlines, etc., in order to maximize what you can accomplish in your role.

- If medical home/asthma, allergy and anaphylaxis is not a priority of your chapter’s leadership, ask if there is any consideration that can be given to adding it to the chapter’s agenda.

- End the discussion by asking how you can follow up on these issues.

- After your meeting, remember to send a follow-up letter of thanks and next steps. Remember to address the president’s letter to his/her practice address.

October 13, 2014
Section 3
Building Effective Partnerships

Partnerships are an important component of community advocacy efforts. Partners can enhance community engagement in projects, increase community awareness of the issues being addressed and establish a framework for the continued support of services that support child health in communities.

7.42.1 Building Effective Partnerships

- Working in partnerships will help multiply the power of advocacy efforts and build strength in numbers.
- Working in partnerships includes getting other individuals, organizations, alliances, and coalitions involved to accomplish your advocacy goal.
- Getting more individuals and groups involved helps us win on the issues that are important to us.
- Working in partnerships helps us increase the number of people and groups working to improve children’s health and well-being and builds strength.
- When working with others—whether it is an individual or a group—try to understand their motivations and interests.
- Remember that partnerships can include the “usual suspects” as well as unlikely partners. The only way to know if someone will support your issue is by asking.

What are Potential Roles That Pediatricians Can Play at the Community Advocacy Level? Some examples of the role that you as a pediatrician could play in community advocacy could include:

- Partner with child advocacy organizations in your area
- Inform community leaders, decision-makers, and elected officials about issues that are affecting children in your community
- Invite decision-makers to visit your professional setting or community project
- Provide testimony and telling your story at community forums, events, and in your local media
• Serve on the board of an organization that supports children’s health and well-being or children’s interests such as a school board

• Offer medical expertise to schools, youth organizations or institutions, and child care centers

• Ask parents, teachers, and other health care professionals and clinicians in your area to get involved in local efforts to improve children’s health and well-being

• Initiate a community project or forming a partnership, alliance, or coalition to address a problem

Visit the AAP Web site to learn more.
PRESENTATION

ADVOCACY

INTRODUCTION
PRESENTATION OVERVIEW

• Designed to make it easier for you to advocate on behalf of children and profession of pediatrics.
  www.aap.org/moc/advocacyguide

• AAP Advocacy Guide
  • Contains the following sections:
    • The What and Why’s of Advocacy
    • Pediatricians are Natural Advocates
    • Getting Comfortable by Learning the Process
    • Core Advocacy Skills
    • Broadening Participation
    • Media Advocacy and Communications
    • Political Campaigns and Elections

WELCOME

• Advocacy is central to AAP mission and one of the top reasons pediatricians join the AAP.

• AAP state chapters are actively engaged in advocacy activities and serve as a source of assistance and support.

• Growing number of pediatricians advocating on behalf of children’s health and well-being.
THE WHAT AND WHYS OF ADVOCACY

An overview of what advocacy is and why it matters to pediatricians.

ADVOCACY DEFINED

• **Advocacy**: Speaking out on your patients’ behalf.

• There are **three levels of advocacy**:
  1) Individual
  2) Community
  3) State and federal advocacy
FURTHER DEFINITIONS OF ADVOCACY

1) Individual Advocacy: Work you do everyday to improve the health and well-being of individual patients.

2) Community Advocacy: Builds on and reaches beyond individual advocacy by shifting focus from children in your professional setting to children within the community.

3) State and Federal Advocacy: Changing the public policies, laws, and rules at state or federal level and has potential to affect broad systemic change.

WHY ADVOCACY MATTERS GENERALLY

• Provides opportunity to move beyond individual solutions to create broader systemic change.

• Pediatricians can help change community norms and public policy to protect children’s health and well-being.
WHY MOVE BEYOND INDIVIDUAL ADVOCACY

Community and state/federal advocacy:
• Works systemically to raise awareness, educate, and/or provide treatment solutions that can help keep children safe and healthy.

• Collectively gain attention of decision-makers, the media, and the general public to create change on behalf of children’s health and well-being.

ADVOCACY WITHIN THE AAP

“It should be our aim to discover neglected problems and, so far as in our power, to correct evils and introduce reform.” — Isaac Abt, MD, the first AAP President

• AAP founded to assure patient advocacy remains a priority for the profession.

• Advocacy is part of pediatrician training.

• Reflects commitment to not only treat sick and injured children in the professional setting, but also work systemically to correct the injustices that contribute to children’s illnesses and injuries in the first place.
What makes pediatricians powerful advocates and how to incorporate advocacy into your professional setting.

THE PEDIATRICIAN’S STORY: THE FOUNDATION OF ADVOCACY

• Your patients’ stories put a human face on broader issues that need to be changed.

• Your story makes the issue real in a way that fact sheets and statistics alone do not.

• Your story can capture the attention of community leaders, elected officials, the media, and the general public, and help propel your issues and concerns forward.
PEDIATRICIANS UNIQUELY QUALIFIED TO ADVOCATE

- **Credibility** by position, reputation, experience.

- **Skill set:** Advocacy skills are not much different from the direct care skills you use everyday. Should be 2 words every day.

- **Strength in numbers:** You are one of many, both within your profession and within your community, who cares about children’s health and well-being.

FITTING ADVOCACY INTO YOUR PROFESSIONAL RESPONSIBILITIES

- **Doesn’t require a lot of time:** Can affect change in as little as an hour a month or less or as much as multiple hours a week.

- **Prioritize your interests:** Don’t have to be an advocate on every issue.

- **AAP state chapters** help to focus and concentrate these efforts.
GETTING COMFORTABLE BY LEARNING THE PROCESS

An overview of the community, state, and federal advocacy processes.

GETTING STARTED

• Don’t need to be expert on process.

• Many pediatricians find it helpful to have a basic understanding of how the community, state and federal advocacy process works as they engage in advocacy efforts.
ESSENTIALS OF COMMUNITY ADVOCACY

• Born out of belief that children’s health is influenced by social, economic, environmental, and political factors within a community.

• Often includes organized activities and partnerships.

• May relate to local community-based initiatives, school board representation, or legislative processes such as city or county government.

• The different venues for community advocacy allows you to get involved in ways that best fit your interests.

STATE AND FEDERAL GOVERNMENT

• State and federal advocacy is about changing public policies and laws that affect children’s health.

• Policies, legislation, regulations, or judicial actions can happen at the state or federal level.

• State and federal government has three independent components:
  • Legislative branch makes the laws
  • Executive branch carries out the laws
  • Judicial branch interprets the laws
STATE ADVOCACY ESSENTIALS

• State legislatures are increasingly active players in the day-to-day governing of the country and are critical to the formation of public health policy.

• Each state operates under a different law-making process, but many commonalities exist among states.

• Legislative sessions vary from state to state and year to year.

• The governor is the chief executive of a state and is responsible for the administration of the government.

• Your state AAP chapter can provide you with more information about your state’s legislature.

FEDERAL ADVOCACY ESSENTIALS

• The United States Congress has two chambers – the Senate and the House of Representatives. Each chamber has its own leadership, its own committee structure, and its own set of rules.

• Each state has two senators representing the entire state. The number of representatives for each state depends upon the state’s population.

• The executive branch consists of the president and the various departments of the federal government.
JUDICIAL ADVOCACY ESSENTIALS

• Courts have historically been active players in the development of public policy.

• Courts across the country face similar legal battles and judicial challenges and are likely to look to judicial trends in other states.

• Judicial advocacy differs from the direct contact that exists when working with a legislature, state agency, or state official.

CORE ADVOCACY SKILLS

Identifying the issues you care about and persuading the people who make decisions on your issues to act.
IDENTIFYING ISSUES YOU CARE ABOUT

• There are many problems that affect the lives of your patients and your ability to provide care and treatment. These individual problems are often part of a broader issue.

• Many of the broader issues that children and pediatricians face can be resolved through changing community norms or systemic policy change.

• When beginning your advocacy efforts, choose issues that reflect your personal interests and the unique stories you see in your professional setting.

SETTING GOALS TO ADVANCE YOUR ISSUE

• Creating tangible community or public policy change is critical to advocacy.

• Pediatricians get involved because they want to fight for something and want to win victories.

• Winning on children’s health issues comes from defining and setting clear goals. When setting goals:
  • Be realistic.
  • Think incrementally.
  • Think broadly: there is no one definition of winning.
INFLUENCING DECISION-MAKERS

• For every issue you care about, there is a decision-maker who can affect or influence the outcome.

• Decision-makers could include:
  • Elected or appointed officials
  • Influential community members.
  • CEOs or administrators of community institutions who serve customers or members of the community.
  • Other professional, civic, youth, business, labor, religious, or educational leaders.

MOTIVATING DECISION-MAKERS TO ACT

• Effective advocacy involves identifying and persuading these decision-makers to act on behalf of your issue.

• It is important to understand what motivates decision-makers:
  • **Elected or appointed officials:** Influenced by what their constituents think and value.
  • **Community leaders:** Are usually not elected, but their position and scope of influence depends on them being viewed as credible, well-liked, or fair. They are influenced by public opinion, but in a less direct way than an elected official.
CONTACTING YOUR DECISION-MAKERS

Decision-makers influenced by personal contact:

- The more personal the better!
- Include a concrete or not direct “ask”.
- Communicate more than once.
- If elected official, state you are a constituent.

SUSTAINING YOUR EFFORTS OVER TIME

- Getting decision-makers to act on behalf of your issue may not happen overnight.
- Important to recognize and celebrate your progress along the way.
- Keep in mind that your advocacy is not occurring in isolation
WE’RE NOT ALONE: BROADENING PARTICIPATION

Using your influence to build strength in numbers by getting others involved in advocating on behalf of children’s health and well-being.

BUILDING STRENGTH IN NUMBERS

• As a pediatrician, you are both a credible and natural advocate for children and your profession.

• However, even with compelling issues, a powerful story and ongoing advocacy, there is a greater chance of winning when we build strength in numbers.

• There are two ways to build strength in numbers:
  1) Getting more people involved.
  2) Getting more organizations involved.
WHY GET MORE PEOPLE INVOLVED

• Generates hope and excitement for your issue.

• The more others see they are not alone, the more they will be willing to advocate and believe that a broader solution is possible.

• More people means increased pressure on decision-makers to act.

• Opposition to your issues frequently emerges. Strength in numbers is one of the best ways to counter it.

HOW TO GET MORE PEOPLE INVOLVED

• Begin with a recognition that some people may be unfamiliar with advocacy work and therefore, hesitant to get involved.

• Start with people you already know and who care about children’s health.

• Ask people (— a natural and acceptable thing to do.)
  • Connect your issue to other’s self-interests.
  • Convey why your issue is important and why their help is needed.
  • Have a concrete request and be clear about the time commitment.
WHY GET MORE ORGANIZATIONS INVOLVED

• Creates perception that the issue has visible and wide-ranging support.

• Further captures attention of decision-makers.

• Demonstrates collective power.

HOW TO GET ORGANIZATIONS INVOLVED

• Choose organizations with common interests.

• Understand the organization’s processes.

• Balance resources against the challenges.

• Don’t forget about non traditional allies.
Overview of how to use the media and communication vehicles to reach a broader audience.

WHAT IS MEDIA ADVOCACY AND COMMUNICATIONS

Intentional use of any type of media or communication mechanism to bring about awareness and change on behalf of your issue.

- **Media advocacy**: Using media (newspapers, magazines, television, and internet) to reach broader audience in order to build awareness on behalf of your issue and gain more attention from decision-makers.

- **Communications advocacy**: Broad term that describes any material and mechanism (other than the media) used to create awareness around your issue, get others involved, or influence decision-makers.
WHY MEDIA ADVOCACY AND COMMUNICATIONS

• Persuades decision-makers to act because they believe public is paying attention.

• Increases likelihood that more people will get involved because they are aware of issue and how they can help change circumstances affecting the children they know and care about.

• Establishes credibility on behalf of your issue by demonstrating how that issue affects many people and deserves the public’s attention.

MEDIA ADVOCACY AND COMMUNICATIONS POINTERS

Two important things to keep in mind when using media and communications to advance your issue:

1) Your message.
2) How you deliver your message.
YOUR MESSAGE

• Message is the core statement of why your issue is important and should be the underpinning of all your media and communications work.

• Effective messages:
  • Create consistency in the way your issue is talked about and cuts across the many stories that relate to your issue.
  • Are easily understood and can they be internalized and repeated by others.
  • Convince people that your issue is something they can support.

HOW TO DELIVER YOUR MESSAGE

• Combine your message with personal stories to illustrate the importance of your message and put a human face on issue.

• Connect your message to what is happening locally.

• Highlight solutions and inform others of how they can help bring about a solution.
How pediatricians can use the campaign and electoral process in a nonpartisan manner to elevate children’s health and well-being.

WHY CAMPAIGNS AND ELECTIONS MATTER

• Provide opportunity to demonstrate to decision-makers that pediatricians and others are voting with children’s health in mind.

• Elect people who are willing to make children’s health a priority results in better public policies and initiatives for children’s health.

• Offer another way to educate elected officials, candidates and votes about children’s health.

• Pediatricians can establish themselves as a constituency that deserves the attention of those running for office.
KEEPING THE RULES IN MIND

• You can engage in almost any political campaign or election activity as a public citizen, but political and election activity on behalf of the AAP has some restrictions.

• Certain political and election activities are restricted or prohibited due to your chapter or organization’s tax status.

• If you are acting as a public citizen, you cannot use your AAP title, as that can imply AAP endorsement.

• The AAP Division of State Government Affairs and the Department of Federal Affairs can provide more information about permissible nonpartisan political campaign and election activities.

USE NONPARTISAN ELECTION WORK TO ADVANCE YOUR ISSUE

Voter registration:
• Helps assure that people who care about children’s health issues are able to demonstrate their care and concern at the poll.

Voter education:
• Provides voters with tools to learn about candidate’s position on issues that matter to them.

Voter mobilization, aka Get-Out-The-Vote (GOTV):
• Ensures voters get to the polls on Election Day to cast their ballots on behalf of children’s health.
CANDIDATE FORUMS

• Inviting political candidates to events to discuss children’s health issues is an important way for child advocates to make an impact during campaign and election cycles.

• AAP Division of State Government Affairs can help you get involved in nonpartisan campaign work.

CAMPAIGN AND ELECTION ESSENTIALS

• Don’t forget about the rules.

• Make the connection between children’s health and voting personal.

• Leverage media and communications along with personal contact.

• Remember that election activities don’t end on election day.
WE’RE HERE TO HELP

An overview of how the AAP can support you in your advocacy efforts.

THE AAP IS HERE TO HELP

• Your state AAP Chapter is the first line of assistance and can help provide you with tools and support.

• The national AAP also has tools and resources to help you be a successful advocate.
AAP DIVISION OF COMMUNITY-BASED INITIATIVES

• Membership opportunity, grants, technical assistance, and resources in community health and child advocacy

• Assistance with curriculum development, and residency training.

• [http://www.aap.org/commpeds/docbi/](http://www.aap.org/commpeds/docbi/)

• Contact us at 800.433.9016, ext. 7085 or docbi@aap.org

AAP DIVISION OF STATE GOVERNMENT AFFAIRS

• E-updates provide pediatricians with the latest state advocacy news and issues and include feature stories and links to valuable resources.

• AAP Chapter Advocacy Summit provides advanced advocacy training.

• [http://www.aap.org/moc/stgovtaffairs/](http://www.aap.org/moc/stgovtaffairs/)

• Contact us at 800.433.9016, ext. 7092 or stgov@aap.org
AAP DEPARTMENT OF FEDERAL AFFAIRS

• FAAN Alert: E-mail alert provides pediatricians with updates from Washington DC and makes calls to action on behalf of federal legislation.

• AAP Legislative Conference provides training and updates on a child health issues and culminates with meetings with your elected officials on Capitol Hill.

• http://aap.grassroots.com/

• Contact us at 800.336.5475 or kids1st@app.org
Getting to Know Title V

For more information contact:
3701 San Mateo Blvd. NE, Suite 103, Albuquerque, NM 87110
(505) 872-4774 Fax (505) 872-4780
www.familyvoices.org

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A national grassroots advocacy network of families and friends founded in 1992

Advocating on behalf of CYSHCN for:
- Family-centered, community-based, comprehensive, coordinated, culturally competent care
- Families as decision makers
- Essential partnerships between families and professionals

Family Voices thanks the former Title V Advisory Committee for their help with this publication:
- Susan Colburn (AL)
- Rodney Farley (AR)
- Lyn Thoreson-Land (OK)
- Phyllis Landry-Ratcliff (LA)
- Ruth Walden (NY)
Title V

The Nation’s oldest Federal-State partnership to *improve the health of all mothers, children, and youth including children and youth with special health care needs and their families.*

Title V Administration

**Federal:**
- U.S Department of Health and Human Services
  - Health Resources and Services Administration (HRSA)
  - Maternal and Child Health Bureau (MCHB)
    - Division of State and Community Health
      - administers the provisions of Title V

**State:**
- Maternal and Child Health (MCH)
- Children with Special Health Care Needs (CSHCN)
  - programs most often in state health departments
Background

1912 Children’s Bureau established – forerunner of the Maternal and Child Health Bureau

1921 Sheppard-Towner Act – first public health grants to states (opposed by many – American Medical Assoc., Catholic Church)

1930 White House Conference on Children → Children’s Charter: detailed needs in health, education, welfare, and protection.

Formation of the American Academy of Pediatrics

“Sometimes when I get home at night in Washington I feel as though I had been in a great traffic jam... In that traffic jam there are all kinds of vehicles moving up toward the Capitol... conveyances of the Army... limousines in which the Department of Commerce rides... it becomes more congested and more difficult, and then because the responsibility is mine and I must, I take a very firm hold on the handles of the baby carriage and I wheel it into traffic.”

Grace Abbott, Chief, Children’s Bureau

“I am mighty glad so many people in America are taking up the children’s work. Being a ranchman and a farmer, and also a child owner, I have often wished that when one of my children get sick, I could wire or call some government expert and have him look after them, like I can do if one of my cows or pigs get some disease.”

Will Rogers, social commentator, humorist
Title V History

1935 Authorized as Title V of the Social Security Act

1969 Title V administration transferred to the Public Health Service

1981 OBRA 81* - converted Title V to a Block Grant**
(combining 7 programs: MCH/CSHCN, SSI, lead screening, hemophilia treatment centers, Sudden Infant Death Syndrome counseling programs, genetic diseases, adolescent programs)

* Omnibus Budget Reconciliation Act
** Block Grants – Set amount of federal money given to states to carry out programs

1989 OBRA introduced major changes. States’ applications for Title V funding require:
1) needs assessment and priorities
2) measurable objectives
3) budget accountability
4) documentation of matching funds
5) maintenance of efforts
6) public input

Learn More at:
Title V: Federal – State Partnership

• States receive federal $$ based on a formula

• States provide a financial match

Title V authorizes appropriations ($$) to States to:

1. Assure access to quality care, especially for those with low-incomes or limited availability of care;

2. Reduce infant mortality;

3. Provide and ensure access to comprehensive prenatal and postnatal care to women (especially low-income and at risk pregnant women);
4. Increase the number of children receiving health assessments and follow-up diagnostic and treatment services;

5. Provide and ensure access to preventive and child care services as well as rehabilitative services for certain children;

6. Implement family-centered, community based, systems of coordinated care for children with special health care needs; and

7. Provide toll-free hotline and assistance in applying for services to pregnant women with infants and children who are eligible for Title XIX (Medicaid).
In addition, Title V authorizes grant appropriations ($$) to:

- Provide for **SPRANS***, research, and training for MCH and CSHCN, for genetic disease testing, counseling, and information, for grants relating to hemophilia, and for the screening of newborns for sickle cell anemia, and other genetic disorders and follow-up services.

* Special Projects of Regional and National Significance

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Title V requires States to:

- Establish a fair method for allocating funds among such individuals, areas, and localities who need MCH services.
- Apply guidelines for the content of health care assessments and services and for assuring their quality.
- Assure [that] charges, if imposed, will be public, are met for low income mothers and children, and will be adjusted to reflect income, resources, and family size.
Title V requires States to:

• Provide for a toll-free hotline for the use of parents to access information about providers for Title V and Medicaid and about other relevant health care providers.

• Coordinate activities with EPSDT* including periodicity and control standards and ensure no duplication.

• Arrange and carry out coordination agreements for care and services with Medicaid.

* Early and Periodic Screening, Diagnosis and Treatment

Title V requires States to:

• Provide for services to identify pregnant women and infants eligible for Medicaid and assist them in applying for assistance.

• Make the [Title V Block Grant] application public within the State to facilitate comment from any person during its development and after its development.
MCH Populations

- Mothers, Pregnant Women, Infants to Age 1
- Children and Adolescents
- Children and Youth with Special Health Care Needs

Family-Centered Care and Family Involvement with Title V
1992/94: Family Participation* Survey and Conference

Family members:
• participate on advisory councils
• receive financial support for parent activities
• become involved with the Block Grant process
• are involved with in-service trainings
• are paid as staff/consultants
• are from diverse cultures
* (now Form 13 of the Block Grant)

2002: Families in Program and Policy (FIPPS)

Interviews were conducted with State Title V programs to:

1. Learn about progress in family participation with:
   - State MCH Programs
   - State CSHCN Programs

2. Gather materials that support family participation

www.familyvoices.org/work/title_v?id=0012
FiPPs Study: *Progress of Family Involvement in Title V Activities*

- Special Initiatives
- State Performance Measures
- Title V Block Grant
- Support
- Advisory Committees
- As Paid Staff or Consultants

Learning More About:
Partnerships - Families and Title V

- Family Voices Title V materials:
  http://www.familyvoices.org/projects?id=0001
State Public Health History

• When was your public health program first established? Why?

• Who have been some of the interesting and important people associated with it?

• What have been some of the landmark events?

• What are some recent important accomplishments?

State History with Families

• When did families first become part of the public health history in your state?

• What were families' interests?

• What activities were families first involved with?

• How are families involved now?
Goals and Challenges...

- Healthy People 2020 – Health Objectives for the Nation
- Incremental Health Care Reform/Affordable Care Act (ACA)
- Medical Home
- Life Course Model
- Health Disparities
- Health Care Quality
- Workforce
- Government Performance and Results Act (GPRA)

Title V
Block Grant & Performance Measures
**MCH Pyramid**

**DIRECT HEALTH CARE SERVICES:**
(Basic Health Gap Filling Services & Health Services for CSHCN)

**ENABLING SERVICES:**
(Transportation, Translation, Outreach, Respite Care, Health Education, Family Support Services, and Purchase of Health Insurance)

**POPULATION-BASED SERVICES:**
(Newborn Screening, Lead Screening, Immunizations, Sudden Infant Death Syndrome Counseling, Oral Health, Injury Prevention, Nutrition, and Outreach/Public Education)

**INFRASTRUCTURE BUILDING SERVICES:**

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**Family Pyramid**

**Direct Actions**
- hugs
- dinner on the table
- brush those teeth

**Enabling Activities**
- driving to the doctor
- grocery shopping
- selecting a health plan

**Health Promotion/Disease Prevention Actions (Population-Based Activities)**
- planning home fire drills
- posting emergency numbers
- annual health checkups and immunizations

**Basic Family Promises (Infrastructure Activities)**
- food
- housing
- clothing
- health
- education
- recreation
- social/emotional
- spiritual/moral
Title V Needs Assessments

- Submitted every 5 years (2010, 2015, 2020)
- Overview of health status by MCH population
- Description by the four levels of the pyramid
- List of 10 priority needs

MCHB Performance Measures

- All State Title V programs collect data on 18 National Performance Measures
- MCHB discretionary grants collect data on additional Performance Measures
Title V Block Grants: Accountability

- State reviews occur with Federal and State staff and outside experts, including families
- Extensive narrative description of state Title V services with special attention to each performance and outcome measure
- Completion of required reports and financial data tables

State Title V Block Grant Annual Report

- What the State has accomplished
- States’ performance and assurance of proper expenditure of funds
- Description of program activities
- Documentation of progress toward meeting performance measures
- Consistency between Report and Application
Annual Report

2

**States must show that:**

- 30% of funds are spent on preventive and primary care for children
- 30% of funds are spent on CYSHCN
- No more than 10% of funds are spent on program administration

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Annual Report

3

**Title V Performance & Outcome Measures**

- ✔️ 18 national performance measures
- ✔️ 7-10 state performance measures (at least one for CYSHCN)
- ✔️ 6 health outcome measures (may also develop 1 additional state measure)
State Title V Block Grant Annual Application

- State’s plan for the coming year
- Relationship of priority needs, performance measures, and capacity and resources of the state program
- Described by four levels of the pyramid

Families and Title V Block Grants

- Since 1997 family members have served as reviewers:
  - All States and Territories have been reviewed by family members
- Some States bring family members to reviews as part of their state teams

This is a great learning process - we learn as much as we give!
- Parent Reviewer

www.familyvoices.org/work/title_v?id=0007
What Family Reviewers say about the Block Grant Process:

"I recommend it for anyone wanting to really understand the Title V system."  
"Each state is different and has unique challenges, but recognizing how resources are being utilized – and to what outcomes – has been enlightening."

"The review was an exceptional experience – I was truly welcomed as a team member."

"We're ahead of the curve as far as parent involvement is concerned."

"Very eye-opening to see what other states are doing and where we could vastly improve."

Want to learn more?  
Contact Your state MCH /CSHCN Director or Family Voices

What is Title V Information System (TVIS)?

The Title V Information System is a great way to learn about Maternal Child Health resources and data for all families and children, including children with special health care needs. It includes snapshots of each state.

Access at:  
https://perfdata.hrsa.gov/mchb/TVISReport
default.aspx
Title V: Maternal & Child Health and Children with Special Health Care Needs Contact Sheet (2014)

**Alabama**
Maternal & Child Health
Chris R. Haag, MPH
Deputy Director, Bureau of Family Health Services
Alabama Dept. of Public Health, PO Box 303017
Montgomery, Alabama 36130-3017
Phone: 334/206-5331
Email: chris.haag@adph.state.al.us

Children with Special Health Care Needs
Melinda Davis, MS, CCC-A CPHL
Assistant Commissioner
Children’s Rehabilitation Service
602 S. Lawrence St.
Montgomery, Alabama 36104
Phone: 334/293-7049
Email: melinda.davis@rehab.alabama.gov

**Arkansas**
Maternal & Child Health
Bradley Planey
Associate Branch Chief
4815 West Markham Street, Slot 16
Little Rock, AR 72205
Phone: 501/661-2531
Fax: 501/661-2464
Email: Bradley.Planey@Arkansas.gov

Children with Special Health Care Needs
Iris Fehr
Interim CSHCN Director
P.O. Box 1437, Slot S-5380
Little Rock, AR 72203
Phone: 501/682-8213
Fax: 501/682-8247
Email: Iris.Fehr@arkansas.gov

**California**
Maternal & Child Health
Shabbir Ahmad, DVM, MS, PhD
MCAH Title V Director
615 Capitol Avenue, MS 8304, PO Box 997420
Sacramento, CA 95899-7420
Phone: 916/650-0300
Fax: 916/650-0305
Email: shabbir.ahmad@cdph.ca.gov

Children with Special Health Care Needs
Louis R. Rico
Chief, Systems of Care Division
1515 K Street, Room 400, MS 8100, PO Box 997413
Sacramento, CA 95899-7413
Phone: 916/449-5240
Fax: 916/327-1106
Email: Louis.Rico@dhcs.ca.gov

**Arizona**
Maternal & Child Health
Mary Ellen Cunningham
Chief, Bureau of Women’s and Children’s Health
Arizona Department of Health Services
150 N. 18th Ave.
Ste. 320
Phoenix, AZ 85007
Phone: 602/364-1419
E-mail: mary.ellen.cunningham@azdhs.gov

Children with Special Health Care Needs
Marta Urbina Chief, Office for Children with Special Health Care Needs Arizona Department of Health Services 150 N. 18th Ave. Ste. 320 Phoenix, AZ 85007
Phone: 602/364-1496
E-mail: marta.urbina@azdhs.gov

**Alaska**
Maternal & Child Health
Stephanie Birch, MPH, MS, FNP
Section Chief
3601 C Street Suite 322
Anchorage, AK 99503-7123
Phone: 907/334-2424
Fax: 907/269-3465
Email: stephanie.wrightsman-birch@alaska.gov
**Colorado**

**Maternal & Child Health**
Karen Trierweiler, MS, CNM  
Center for Healthy Families and Communities  
CO Dept. of Public Health & Environment  
4300 Cherry Creek Drive South  
PSD-MCH-A4  
Denver, CO 80246  
Phone: 303/692-2481  
E-mail: karen.trierweiler@state.co.us

**Children with Special Health Care Needs**
Rachel Hutson Director, Children & Youth Branch  
Colorado Department of Public Health and Environment  
4300 Cherry Creek Drive South PSD-CASH-A4  
Denver, CO 80246-1530  
Phone: 303/692-2365  
E-mail: rachel.hutson@state.co.us

**Connecticut**

**Maternal & Child Health**
Rosa M. Biaggi, MPH, MPA  
Chief  
Family Health Section  
CT Department of Public Health  
410 Capitol Ave., MS#11-MAT  
PO Box 340308  
Hartford, CT 06134-0308  
Phone: 860/509-8074  
E-mail: Rosa.Biaggi@ct.gov

**Children and Youth with Special Health Care Needs**
Mark Keenan, Director  
Children and Youth with Special Health Care Needs  
CT Department of Public Health  
410 Capitol Ave., MS#11-MAT  
PO Box 340308  
Hartford, CT 06134-0308  
Phone: 860/509-8074  
E-mail: mark.keenan@ct.gov

**District of Columbia**

**Title V MCH Director**
Brenda Kelly  
Interim Senior Deputy Director, CHA  
899 North Capitol Street, NE  
Washington, DC 20002  
Phone: 202/442-9341  
E-mail: brenda.kelly4@dc.gov

**CSHCN Director**
Sarah Aleem, PhD  
Child and Adolescent School Health, Bureau Chief  
899 North Capitol Street, NE  
Washington, DC 20002  
Phone: 202/442-9338  
E-mail: sarah.aleem@dc.gov

**Florida**

**Maternal & Child Health**
Kris-Tena Albers, C.N.M., A.R.N.P  
Title V MCH Director  
Chief, Bureau of Family Health Services  
Florida Department of Health, Division of Community Health Promotion  
4052 Bald Cypress Way, Bin A-13  
Tallahassee, FL 32399-1723  
Phone: 850/245-4467  
E-mail: Kris-Tena_Albers@doh.state.fl.us

**Children with Special Health Care Needs**
Charlotte Curtis  
Bureau Chief, Network Operations and Director, Title V Children with Special Health Care Needs (CSHCN 4052 Bald Cypress Way, Bin A06  
Tallahassee, FL 32399-1723  
Phone: 850/245-4222  
E-mail: charlotte.curtis@flhealth.gov
**Georgia**

Maternal & Child Health  
Seema Csukas  
Director, Maternal and Child Health Section  
Georgia Department of Public Health  
2 Peachtree Street, NW, 11th floor  
Atlanta, GA 30303  
Phone: 404/657-2851  
Fax: 404/657-7307  
E-mail: secsukas@dhr.state.ga.us

Children with Special Health Care Needs  
Audrey Blake  
CYSHCN Director  
2 Peachtree St, NW 11th floor  
Atlanta, GA 30303  
Phone: 404/657-2672  
Email: amblake@dhr.state.ga.us

**Hawaii**

Maternal & Child Health  
Danette Wong Tomiyasu  
Chief, Family Health Services Division  
State of Hawaii, Department of Health  
1250 Punchbowl Street, Room 216  
Honolulu, HI 96813  
Phone: 808/586-4121  
E-mail: danette.tomiyasu@doh.hawaii.gov

Children with Special Health Care Needs  
Patricia L. Heu, MD  
Chief, CSHCN Branch  
HI State Department of Health  
741 Sunset Avenue  
Honolulu, HI 96816  
Phone: 808/733-9070  
E-mail: patricia.heu@doh.hawaii.gov

**Idaho**

Maternal & Child Health  
Kris Spain, MS RD LD  
Chief, Bureau of Clinical and Preventive Services  
450 W State, 4th Floor  
Boise, ID 83720  
Phone: 208/334-6960  
Fax: 208/334-0614  
Email: spanik@dhw.idaho.gov

Children with Special Health Care Needs  
Jacqueline Watson  
Manager, Maternal and Child Health Program

Idaho Department of Health and Welfare  
450 W. State Street  
Boise, ID 83720-0036  
Phone: 208/334-5963  
E-mail: danielj@dhw.idaho.gov

**Illinois**

Maternal & Child Health  
Brenda Jones DHSc, RN, MSN, WHNP-BC  
Deputy Director  
Illinois Department of Public Health  
535 W Jefferson Street  
Springfield, Illinois 62761  
Phone: 217/785-1050  
Fax: 312/793-4666  
Email: Brenda.L.Jones@illinois.gov

Children with Special Health Care Needs  
Thomas Jerkovitz Director University of Illinois-Chicago, Division of Specialized Care for Children  
3135 Old Jacksonville Road  
Springfield, IL 62704-6488  
Phone: 217/558-2350  
E-mail: tfjerkov@uic.edu

**Indiana**

Division of Maternal & Child Health  
Bob Bowman  
Interim Director, Maternal and Child Health  
2 North Meridian Street  
Indianapolis, IN 46204  
Phone: 317/233-1231  
Fax: 317/234-2995  
Email: bobbowman@isdh.in.gov

Children’s Special Health Care Services  
Shirley Payne  
Interim Director, Children’s Special Health Care Services  
2 North Meridian Street  
Indianapolis, IN 46204  
Phone: 317/233-7046  
Fax: 317/233-1342  
Email: SPayne@isdh.in.gov

**Iowa**

Maternal and Child Health  
Gretchen Hageman  
Title V Director Iowa Department of Public Health, Bureau of Family Health  
321 E 12th Street  
Lucas Building, 5th Floor  
Des Moines, IA 50319
Children and Youth with Special Health Care Needs  
Debra B. Waldron, MD, MPH, FAAP  
Director and Chief Medical Officer Child Health  
Specialty Clinics University of Iowa  
100 Hawkins Drive (247-B)  
Iowa City, IA 52242  
Phone: 319/384-7292  
Email: debra-waldron@uiowa.edu  
Internet site: www.chsciowa.org

**Kansas**  
Maternal and Child Health  
Rachel Berroth  
Bureau of Family Health Director  
1000 SW Jackson Street, Ste 220  
Topeka, KS 66612  
Phone: 785/296-1310  
Fax: 785/296-8616  
Email: rberroth@kdheks.gov

Children and Youth with Special Health Care Needs  
Heather Smith  
Special Health Services Section Director  
1000 SW Jackson Street, Ste 220  
Topeka, KS 66612  
Phone: 785/296-1316  
Fax: 785/296-8616  
Email: hsmith@kdheks.gov

**Kentucky**  
Title V Director  
Ruth Ann Shepherd, M.D., FAAP, CPHQ Division Director, Division of Adult & Child Health Improvement  
KY Department of Public Health  
275 East Main Street HS2W-A  
Frankfort, KY 40621  
Phone: 502/564-4830  
E-mail: ruth.shepherd@ky.gov

Commission for Children with Special Health Care Needs  
Jackie Richardson Executive Director, Kentucky Commission for Children with Special Health Care Needs  
Kentucky Department for Public Health  
310 Whittington Parkway Suite 200  
Louisville, KY 40222  
Phone: 502/429-4430 (281)  
E-mail: Jackie.Richardson@ky.gov

**Louisiana**  
Maternal and Child Health Program  
Amy Zapata, MPH  
Director, Bureau of Family Health  
Louisiana Office of Public Health  
1450 Poydras Street, Room 2032  
New Orleans, LA 70112  
Phone: (504) 568-3504  
Email: amy.zapata@la.gov

Children’s Special Health Services Program  
Susan Berry, MD, MPH  
Director, CSHS Program  
Louisiana Office of Public Health  
1450 Poydras Street, 19th Floor  
New Orleans, LA 70112  
Phone: 504/568-5055  
Email: susan.berry@la.gov

**Maine**  
Maternal & Child Health  
Valerie J. Ricker, MSN, MS  
Assistant Director, Division of Population Health  
Maine Center for Disease Control and Prevention  
Key Bank Plaza, 7th floor  
11 State House Station  
Augusta, ME 04333-0011  
Phone: 207/287-4064  
Fax: 207/287-5355  
E-mail: valerie.j.ricker@maine.gov

Children with Special Health Care Needs  
Toni Wall, MPA  
Director, CSHN  
Maine Center for Disease Control and Prevention  
Key Bank Plaza, 7th floor  
11 State House Station  
Augusta, ME 04333-0011  
Phone: 208/287-3311  
Fax: 207/287-5355  
E-mail: toni.g.wall@maine.gov

**Maryland**  
Maternal & Child Health  
Ilise Marrazzo
Director, Maternal and Child Health Bureau
201 W. Preston Street
Baltimore, Maryland 21201
Phone: 410/767-5596
Fax: 410/333-5233
Email: ilise.marrazzo@maryland.gov

**Children with Special Health Care Needs**

Donna X. Harris
Director, Office for Genetics & CYSHCN
Maryland Department of Health and Mental Hygiene
201 West Preston Street
Baltimore, MD 21201
Phone: 410/767-5642
Email: dxharris@dhmh.state.md.us

**Massachusetts**

**Title V and Children with Special Health Care Needs**

Director
Ron Benham
Director, Bureau of Family Health and Nutrition
Massachusetts Department of Public Health 250 Washington Street, 5th Floor Boston, MA 02108-4619
Phone: 617/624-5901
Email: ron.benham@state.ma.us

**Michigan**

**Maternal & Child Health**

Stan Bien
Acting Title V MCH Program Director
Bureau of Family, Maternal and Child Health
201 Townsend Street
Lansing, Michigan 48933
Phone: 517/335-8922
Fax: 517/335-9032
Email: bien5@michigan.gov

**Children with Special Health Care Needs**

Lonnie D. Barnett
Director, CSHCS Division
320 South Walnut Street
Lansing, MI 48913
Phone: 517/335-5008
Email: barnettl@michigan.gov

**Minnesota**

Susan Castellano MCH Director Minnesota
Department of Health P.O. Box 64882 St. Paul, MN
55164-0882
Phone: 651/201-3872
E-mail: susan.castellano@state.mn.us

**Children with Special Health Care Needs**

Barb Dalbec Minnesota Department of Health
Community and Family Health Division P.O. Box 64882 St. Paul, MN 55164-088
Phone: 651/201-3758
E-mail: barb.dalbec@state.mn.us

**Mississippi**

**Maternal & Child Health**

Kathy Burk
Health Services Director/MCH Director
Mississippi Department of Health
570 E. Woodrow Wilson, Suite 219
Jackson, MS 39215-1700
Phone: 601/576-7472
E-mail: Kathy.Burk@msdh.state.ms.us

**Children with Special Health Care Needs**

Patricia Bailey CSHCN Director Mississippi
Department of Health
P. O. Box 1700 Jackson, MS 39215-1700
Phone: 601/987-3965
E-mail: patricia.bailey@msdh.state.ms.us

**Missouri**

**Maternal & Child Health**

Melinda Sanders, Title V Director
Deputy Director
Division of Community and Public Health
Missouri Department of Health & Senior Services
PO Box 570, 930 Wildwood Drive
Jefferson City, MO 65102-0570
Phone: 573/751-6252
E-mail: melinda.sanders@health.mo.gov

**Children and Youth with Special Health Care Needs**

Steven Cramer, CYSHCN Director
Administrator, Section for Special Health Services
Missouri Department of Health and Senior Services
PO Box 570, 930 Wildwood Drive
Jefferson City, MO 65102-0570
Phone: 573/751-6241
Montana
**Title V/MCH Director**
Ann Buss, Supervisor
Maternal Child Health Coordination
Family and Community Health Bureau
Montana Department of Public Health & Human Services
Phone: 406/444-4119
E-mail: abuss@mt.gov

**Children with Special Health Care Needs**
Denise Brunett, Supervisor
Children’s Special Health Services
Family and Community Health Bureau
Montana Department of Public Health & Human Services
Phone: 406/444-3617
E-mail: dbrunett@mt.gov

Nebraska
**Maternal & Child Health**
Paula Eurek, Administrator
Lifespan Health Services
DHHS
301 Centennial Mall South,
PO Box 95026
Lincoln, NE 68509-5026
Phone: 402/471-0196
Email: paula.eurek@nebraska.gov

**Children with Special Health Care Needs**
Heather Krieger
Administrator, State/Grant Funded Programs Unit
PO Box 95026
Lincoln, Nebraska 69509-5026
Phone: 402-471-9155
Fax: 402-471-6352
Email: heather.krieger@nebraska.gov

New Hampshire
**Maternal and Child Health**
Patricia Tilley
Chief, Bureau of Population Health and Community Services/Title V Director
29 Hazen Drive
Concord, NH 03301
Phone: 603/271-4526
Email: ptilley@dhhs.state.nh.us

**Children with Special Health Care Needs**
Elizabeth Collins, RN-BC, CSHCN Director Special Medical Services
129 Pleasant St
Concord, NH 03301
Phone: 603-271-8181
E-mail: ecollins@dhhs.state.nh.us

New Jersey
**Maternal and Child Health**
Gloria Rodriguez
Assistant Commissioner
P.O. Box 364
Trenton, NJ 08625
Phone: 609/292-4043
Email: gloria.rodriguez@doh.state.nj.us

**Children with Special Health Care Needs**
Dr. Marilyn Gorney-Daley
Service Directors SCHEIS
P.O. Box 364
Trenton, NJ 08625
Phone: 609/292-4043
Email: gloria.rodriguez@doh.state.nj.us

New Mexico
**Maternal & Child Health**
Denita Richards, R.N.
Family Health Bureau Chief/Title V MCH Director
2040 S. Pacheco
Santa Fe, NM 87505
Phone: 505/476-8901
Email: denita.richards@state.nm.us

**Children with Special Health Care Needs**
Susan Chacon CSHCN Director New Mexico New Mexico Department of Health Children's Medical Services 2040 S. Pacheco Santa Fe, NM 87505
Phone: (505) 476-8899
New York
Maternal & Child Health Rachel DeLong, MD, MPH Director, Division of Family Health
New York State Department of Health
890 Corning Tower
Empire State Plaza
Albany, NY 12237
Phone: 518/473-7922
E-mail: rmd07@health.state.ny.us

Children with Special Health Care Needs
Susan Slade, RN, MS, MCHES CSHCN Director
Office of the Medical Director
Division of Family Health
New York State Department of Health
894 Corning Tower
Albany, New York 12237
Phone: 518/473-9883
Email: sjs11@health.state.ny.us

North Carolina
Maternal & Child Health
Kevin Ryan, MD, MPH
Chief, Women’s and Children’s Health
NC Dept. of Health and Human Services
1928 Mail Service Center
Raleigh, NC 27699-1928
Phone: 919/707-5512
E-mail: kevin.ryan@dhhs.nc.gov

Children with Special Health Care Needs
Carol Tant, MPH
Branch Head, Children and Youth
NC Dept. of Health and Human Services
1928 Mail Service Center
Raleigh, NC 27699-1928
Phone: 919/707-5610
E-mail: carol.tant@dhhs.nc.gov

North Dakota
Maternal & Child Health
Kim Mertz
Director, Division of Family Health and Title V
600 East Boulevard Avenue, Dept. 301
Bismarck, ND 58505-0200
Phone: 701/328-2493
E-mail: kmertz@nd.gov

Children with Special Health Care Needs
Tamara Gallup-Millner, RN, MPA
Division Director, Children’s Special Health Services
North Dakota Department of Health
600 East Boulevard Avenue, Dept. 301
Bismarck, ND 58505-0200
Phone: 701/328-2436
E-mail: Tgallupmillner@nd.gov

Ohio
Maternal & Child Health
Karen Hughes, M.P.H.
Division Chief, Family & Community Health
Ohio Department of Health
246 N. High Street
Columbus, OH 43215
Phone: 614/644-7848
Email: karen.hughes@odh.ohio.gov

Children with Special Health Care Needs
Jessica Foster MD, M.P.H., FAAP Physician Administrator, Bureau for Children with Developmental and Special Health Needs Ohio Department of Health 246 North High Street Columbus, OH 43215
Phone: 614/644-0663
Email: jessica.foster@odh.ohio.gov

Oklahoma
Maternal & Child Health
Suzanna Dooley, APRN-CNP
Chief, Maternal & Child Health Service
OK State Department of Health
1000 NE Tenth Street
Oklahoma City, OK 73117-1299
Phone: 405/271-4480
E-mail: suzannad@health.ok.gov

Children with Special Health Care Needs
Karen Hylton, B.A.
Programs Manager
Oklahoma Department of Human Services
Family Support Services Division
P. O. Box 25352
Oklahoma City, OK 73125
Phone: 405/521-3602
E-mail: Karen.Hylton@okdhs.org
Oregon
Title V Program, contact:
Cate Wilcox, MPH
Title V Director, MCH Section Manager
800 NE Oregon St., Ste. 825
Portland, OR 97232
Phone: 971/673-0299
Email: cate.s.wilcox@state.or.us

Children with Special Health Care Needs, contact:
Marilyn Hartzell, Med
CYSHN Director
P.O. Box 574
Portland, OR 97207
Phone: 503/494-6761
Email: hartzell@ohsu.edu

Pennsylvania
Maternal & Child Health
Melia Belonus Bureau Director Pennsylvania
Department of Health Health & Welfare Building
7th Floor East Wing 625 Forster Street Harrisburg, PA 17120-0701
Phone: 717/787-7192
Email: mbelonus@state.pa.us

Children with Special Health Care Needs
Michelle Connors
Director, Division of Community Systems
Development and Outreach
Department of Health, Bureau of Family Health
Health & Welfare Building, 7th Flr East Wing
625 Forster Street
Harrisburg, PA 17120-0701
Phone: 717/772-2763
E-mail: mconnors@state.pa.us

Rhode Island
Maternal & Child Health
Ana Novais, MA
Executive Director
Division of Community Family Health & Equity
Rhode Island Department of Health
3 Capitol Hill
Providence, RI 02908
Phone: 401/222-5118
Email: ana.novais@health.ri.gov

Children with Special Health Care Needs
Deborah Garneau, MA
Chief, Office of Special Healthcare Needs Division
of Community Family Health & Equity Rhode
Island Department of Health
3 Capitol Hill, Room 302
Providence, RI 02908
Phone: 401/222-5929
Email: deborah.garneau@health.ri.gov

South Carolina
Maternal & Child Health
Brenda Martin
Bureau Director State Department of Health and Environmental Control Maternal and Child Health
Bureau 1751 Calhoun Street Columbia, SC 29201-2606
Phone: 803/898-3780
E-mail: martinby@dhec.sc.gov

Children with Special Health Care Needs Cheryl Waller
Director State Department of Health and Environmental Control Maternal and Child Health
Mills-Jarrett Complex P.O. Box 101106 Columbia, SC 29211
Phone: 803/898-0789
Email: wallercj@dhec.sc.gov

South Dakota
Maternal & Child Health
Darlene Bergeleen, RN, BSN
Family and Community Health Services Administrator
South Dakota Department of Health
600 E Capitol
Pierre SD 57501
Phone: 605/773-4439
Fax: 605/773-5683
Email: darlene.bergeleen@state.sd.us

Children with Special Health Care Needs
Barb Hemmelman, BS
Manager, CYSHCN
SD Department of Health
600 E. Capitol
Pierre, SD 57501-2536
Phone: 605/773-4749
Fax: 605/773-5683
Email: barb.hemmelman@state.sd.us
**Tennessee**

**Maternal & Child Health**
Michael Warren, MD MPH MCH Director
Tennessee Department of Health Cordell Hull Bldg, 425 5th Ave North, 4th Floor Nashville, TN 37243
Phone: 615/741-7353
Email: michael.d.warren@tn.gov

**Children with Special Health Care Needs**
Jacqueline Johnson, MPA
Director, Children’s Special Services
TN Department of Health
425 5th Avenue North, 4th Floor
Nashville, TN 37243
Phone: 615/741-7353
E-mail: Jacqueline.Johnson@tn.gov

**Texas**

**Maternal & Child Health**
Evelyn Delgado
Interim Title V/MCH Director
PO Box 149347, MC 1920
Austin, Texas 78714-8347
Phone: 512/776-7321
E-mail: evelyn.delgado@dshs.state.tx.us

**Children with Special Health Care Needs**
Manda Hall, MD Title V MCH CSHCN Director
Texas Department of State Health Services
P.O. Box 149347
Austin, TX 78714-9347
Phone: 512/776-2567
Email: manda.hall@dshs.state.tx.us

**Utah**

**Maternal & Child Health**
Nan Streeter, MS, RN
Director
Maternal and Child Health Bureau
Utah Department of Health
PO Box 142001
Salt Lake City, UT 84114-2001
Phone: 801/538-6869
E-mail: nanstreeter@utah.gov

**Children with Special Health Care Needs**
Richard S. Harward, Au.D., CCC-A Bureau Director, CYSHCN
Utah Department of Health

**Vermont**

**Maternal and Child Health**
Breena Holmes, MD
Director, Division of Maternal and Child Health
Vermont Department of Health
108 Cherry Street
Burlington, VT 05401
Phone: 802/863-7347
Email: breena.holmes@state.vt.us

**Children with Special Health Care Needs**
Carol Hassler, MD, Medical Director, CSHN
Steve Brooks, Operations Director, CSHN
Vermont Department of Health
108 Cherry Street
Burlington, VT 05401
Phone: 802/863-1324
carol.hassler@state.vt.us

**Virginia**

**Maternal & Child Health**
Lauri Kalanges, MD, MPH
Acting Director, Office of Family Health Services
109 Governor Street, 7th Floor
Richmond, Virginia 23219
Phone: 804/864-7170
Email: lauri.kalanges@vdh.virginia.gov

**Children with Special Health Care Needs**
Sidnee’ Dallas
CSHCN Program Manager
109 Governor Street
Richmond, VA 23219
Phone: 804/864-7716
Email: Sidnee.Dallas@vdh.virginia.gov

**Washington**

**Maternal & Child Health**
Janna Bardi
MCH Director
310 Israel Road SE
Tumwater, WA 98501
Phone: 360 236 3687
E-mail: Janna.Bardi@doh.wa.gov
**Children with Special Health Care Needs**
Maria Nardella
Manager CSHCN Program
WA State Department of Health
PO Box 47880
Olympia, WA 98504-7880
Phone: 360/236-3573
E-mail: maria.nardella@doh.wa.gov

**West Virginia**
Maternal, Child and Family Health
Anne Williams Director, Office of Maternal, Child and Family Health West Virginia Bureau for Public Health 350 Capitol Street, Room 427 Charleston, WV 25301-3714
Phone: 304/558-5388
Email: Anne.a.williams@wv.gov

**Children with Special Health Care Needs**
Christina Mullins, MA
Director
Division of Infant, Child and Adolescent Health
West Virginia Department of Health and Human Resources
350 Capitol Street, Room 427
Charleston, WV 25301-3714
Phone: 304/558-5388
Email: Christina.R.Mullins@wv.gov

**Wisconsin**
Maternal & Child Health
Linda Hale, RN BSN EMT
Chief, Family Health Section
Wisconsin Department of Health Services
1 West Wilson Street, Room 351
Madison, WI 53703
Phone: 608/267-7174
Email: Linda.hale@wi.gov

**Children and Youth with Special Health Care Needs**
Sharon Fleischfresser, MD, MPH
Medical Director
Wisconsin Department of Health Services
1 West Wilson Street, Room 351
Madison, WI 53703
Phone: (608) 266-3674
Sharon.fleischfresser@wi.gov

**Wyoming**
Maternal & Child Health and Children with Special Health Care Needs
Linda McElwain Maternal and Child Health Unit Manager Wyoming Department of Health 6101 North Yellowstone Road Suite 420 Cheyenne, WY 82002-0001
Phone: 307/777-6326
Email: linda.mcelwain@health.wyo.gov
Puerto Rico
U.S. Virgin Islands
Guam
American Samoa
Commonwealth of Northern Mariana Islands
Children’s Health Insurance Program
Plan Activity as of January 14, 2013

Separate State Child Health Plans: 15 States
Medicaid Expansions: 7 States, 5 Territories, and D.C.
Combination Programs: 28 States

Key:
^ Approved CHIP 1115 Demonstrations with Coverage for Adults: 7 (AR, CO, ID, NV, NJ, NM, VA)
# State no longer has a Medicaid expansion program as of September 30, 2002, due to the aging out of the children phased into the Medicaid program under OBRA’90.

Created by CMS CMCS CAHPG DCHIP – 01-14-2013
Children’s Health Insurance Program (CHIP) State Directors

**Alabama**
Cathy Caldwell
Alabama Department of Public Health, CHIP
P.O. Box 303017
Montgomery, Alabama 36130-3017
Phone: 334/206-5568
Email: cathy.caldwell@adph.state.al.us

**Arizona**
Monica Coury
Assistant Director
801 E. Jefferson Street, mail Drop 4200
Phoenix, AZ 85034
Phone: 602/417-4019
FAX: 602/252-6756
E-mail: alma.torres@azahcccs.gov

**Colorado**
Jeanine Draut
1570 Grant Street
Denver, Co 80203
Phone: 303/866-5942
FAX: 303/866-2803
E-mail: jeanine.draut@state.co.us

**Connecticut**
Mark Schaefer, PhD
Acting Director
Medical Care Administration
Department of Social Services
25 Sigourney Street
Hartford, CT 06106-5033
Phone: 860/424-5067

**Georgia**
Sheila Alexander
Program Director
2 Peachtree St., NW
37th Floor
Atlanta, GA 30303
Phone: 404/657-9506
E-mail: salexander@dch.ga.us

**Kansas**
Sharon Johnson
900 SW Jackson St, Suite 900
Topeka, KS 66612
Phone: 785/291-9792
FAX: 785/296-4813
Email: Sharon.Johnson@khpa.ks.gov

**Mississippi**
Betty Williams
Deputy Administrator – Enrollment
Suite 1000, Walter Sillers Building
500 High Street
Jackson, MS 39201
Phone: 601/576-4113
FAX: 601/576-4164
E-mail: betty.williams@medicaid.ms.gov

**Oregon**
Jesse Anderson
State Plan Manager
500 Summer St NE
Salem, OR 97301
Phone: 503/945-6958
FAX: 503/947-1119
Email: jesse.anderson@state.or.us

**Pennsylvania**
Peter Adams
1142 Strawberry Square
Harrisburg, PA 17120
Phone: 717/705-0009
FAX: 717/705-1643
Email: padams@pa.gov

**Texas**
Kay Ghahremani
Deputy Director, Medicaid and CHIP
P.O. Box 85200, MC H-600
Austin, TX 78758
Phone: 512/491-4012
FAX: 512/491-1953
E-mail: Kay.ghahremani@hhsc.state.tx.us
**Utah**
Michael Hales, MPA
Deputy Director
Division of Medicaid and Health Financing
Department of Health
P.O. Box 143101
Salt Lake City, UT 84114-3101
Phone: 801/538-6689
E-mail: mthales@utah.gov

**Vermont**
Russell Frank
312 Hurricen Lane, Suite 201
Montpelier, VT 05495
Phone: 802/879-5932
Email: Russell.Frank@ahs.state.vt.us

**Washington**
Kevin Cornell
CHIP Program Manager
MS 45534
805 Plum St. SE
Olympia, WA 98504-5534
Phone: 360/725-1423
FAX: 360/664-0910
E-mail: kevin.cornell@hca.wa.gov

**West Virginia**
Sharon L. Carte
Executive Director
2 Hale Street, Suite 101
Charleston, WV 25301
Phone: 304/957-7861
Email: brenda.k.jones@wv.gov

**Wyoming**
Susie Scott
Kid Care CHIP Manager
6101 Yellowstone Rd., Suite 210
Cheyenne, WY 82002
Phone: 307/777-6228
FAX: 307/777-7085
Email: susie.scott@wyo.gov
List of State Medicaid Directors

**Alabama**
Stephanie Azar  
**Acting Commissioner**  
Alabama Medicaid Agency  
501 Dexter Avenue, PO Box 5624  
Montgomery, AL 36103-5624  
Phone: (334) 242-5600  
NAMD Region: III

**California**
Toby Douglas  
**Director**  
California Department of Health Care Services  
1501 Capitol Avenue, 6th Floor, MS 0000  
Sacramento, CA 95814  
Phone: (916) 440-7400  
NAMD Region: I

**Alaska**
Margaret Brodie  
**Director, Health Care Services**  
Alaska Department of Health and Social Services  
4501 Business Park Boulevard, Building L  
Anchorage, AK 99503-7167  
Phone: (907) 334-2520  
NAMD Region: I

**Colorado**
Suzanne Brennan  
**Medicaid Director**  
Colorado Department of Health Care Policy and Financing; Medicaid & Child Health Plan (CHP+)  
1570 Grant Street  
Denver, CO 80203-1818  
Phone: (303) 866-5929  
NAMD Region: I

**Arizona**
Tom Betlach  
**Director**  
Arizona Health Care Cost Containment System  
801 East Jefferson, MD 4100  
Phoenix, AZ 85034  
Phone: (602) 417-4711  
NAMD Region: I

**Connecticut**
Kate McEvoy  
**State Medicaid Director**  
Connecticut Department of Social Services  
Medical Care Administration  
25 Sigourney Street  
Hartford, CT 06106  
Phone: (860) 424-5067  
NAMD Region: IV

**Arkansas**
Dawn Zekis  
**Director**  
Division of Medical Services  
Arkansas Department of Human Services  
112 West 8th Street, Slot S401  
Little Rock, AR 72201-4608  
Phone: (501) 682-8740  
NAMD Region: III

**Delaware**
Stephen Groff  
**Medicaid Director**  
Division of Medicaid & Medical Assistance Delaware  
Department of Health and Social Services  
1901 N. Dupont Highway, The Lewis Building  
New Castle, DE 19720  
Phone: (302) 255-9626  
NAMD Region: IV

*As of August 25, 2014*
As of August 25, 2014

District of Columbia
Claudia Schlosberg
Interim Deputy Director and Medicaid Director
District of Columbia Department of Health Care Finance
One Judiciary Square
441 4th Street, NW
Washington, DC 20001
Phone: (202) 442-9075
NAMD Region: IV

Illinois
Theresa Eagleson
Administrator
Illinois Department of Healthcare and Family Services
201 South Grand Avenue East, 3rd Floor
Springfield, IL 62763-0001
Phone: (217) 782-2570
NAMD Region: II

Florida
Justin Senior
Deputy Secretary for Medicaid
Florida Agency for Health Care Administration
2727 Mahan Drive, Mail Stop 8
Tallahassee, FL 32308
Phone: (850) 412-4007
NAMD Region: III

Indiana
Joe Moser
Director of Medicaid
Indiana Family and Social Services Administration
402 West Washington Street, Room W461, MS 25
Indianapolis, IN 46204
Phone: (317) 234-8725
NAMD Region: II

Georgia
Jerry Dubberly
Chief
Medicaid Division
Georgia Department of Community Health
2 Peachtree Street, NW, Suite 36450
Atlanta, GA 30303
Phone: (404) 651-8681
NAMD Region: III

Iowa
Julie Lovelady
Interim Medicaid Director
Iowa Department of Human Services
100 Army Post Road
Des Moines, IA 50315
Phone: (515) 256-4640
NAMD Region: II

Hawaii
Kenneth Fink
Med-QUEST Division Administrator
Hawaii Department of Human Services
601 Kamokila Blvd, Room 518, PO Box 700190
Kapolei, HI 96709-0190
Phone: (808) 692-8050
NAMD Region: I

Kansas
Susan Mosier, MD
Medicaid Director
Kansas Department of Health and Environment
900 SW Jackson Avenue, Suite 900
Topeka, KS 66612
Phone: (785) 296-0461
NAMD Region: II

Idaho
Lisa Hettinger
Division Administrator for Medicaid
Idaho Department of Health and Welfare
450 West State Street,
PTC Building, 10th Floor
Boise, ID 83705
Phone: (208) 334-5801
NAMD Region: I

Kentucky
Lawrence Kissner
Commissioner
Department for Medicaid Services
Kentucky Cabinet for Health & Family Services
275 East Main Street, 6 West A
Frankfort, KY 40621
Phone: (502) 564-4321
NAMD Region: III
Louisiana
Ruth Kennedy
Medicaid Director
Louisiana Department of Health and Hospitals
628 North 4th Street
Baton Rouge, LA 70802
Phone: (225) 342-9240
NAMD Region: III

Minnesota
Ann Berg
Deputy Medicaid Director
Minnesota Department of Human Services
540 Cedar Street, PO Box 64983
St. Paul, MN 55167-0983
Phone: (651) 431-2319
NAMD Region: II

Mississippi
David J. Dzielak
Executive Director
Division of Medicaid
Mississippi Department of Human Services
550 High Street, Suite 1000
Walters Sillers Building
Jackson, MS 39201-1325
Phone: (601) 359-9562
NAMD Region: III

Maryland
Chuck Lehman
Acting Deputy Secretary
Health Care Financing
Maryland Department of Health and Mental Hygiene
201 West Preston Street, Room 525
Baltimore, MD 21201
Phone: (410) 767-4139
NAMD Region: IV

Massachusetts
Kristin Thorn
Acting Medicaid Director
Office of Medicaid
Massachusetts Department of Health and Human Services
1 Ashburn Place, 11th Floor, Room 1109
Boston, MA 02108
Phone: (617) 573-1770
NAMD Region: IV

Michigan
Stephen Fitton
Medicaid Director
Michigan Department of Community Health
400 South Pine Street
Lansing, MI 48913
Phone: (517) 241-7882
NAMD Region: II

Montana
Mary Dalton
State Medicaid Director
Montana Department of Public Health and Human Services
111 North Sanders, PO Box 4210
Helena, MT 59604
Phone: (406) 444-4084
NAMD Region: I

Nebraska
Ruth Vineyard, Courtney Miller, Jeanne Larsen
Deputy Directors, Division of Medicaid & Long-Term Care
Nebraska Department of Health and Human Services
301 Centennial Mall South, 3rd Floor, PO Box 95026
Lincoln, NE 68509-5026
Phone: (402) 471-2135
NAMD Region: II
**Nevada**
Laurie Squatsoff  
*Administrator*  
Division of Health Care Financing and Policy  
Nevada Department of Health and Human Services  
1100 East William Street, Suite 101  
Carson City, NV 89710  
Phone: (775) 684-3677  
NAMD Region: I

**North Carolina**
Robin Cummings  
*Medicaid Director*  
North Carolina Department of Health and Human Services  
1985 Umstead Drive, 2501 Mail Service Center  
Raleigh, NC 27699-2501  
Phone: (919) 855-4100  
NAMD Region: III

**New Hampshire**
Kathleen Dunn  
*Director*  
Office of Medicaid Business and Policy  
New Hampshire Department of Health and Human Services  
129 Pleasant Street  
Concord, NH 03301-6521  
Phone: (603) 271-9421  
NAMD Region: IV

**New Jersey**
Valerie Harr  
*Director*  
Division of Medical Assistance and Health Services  
New Jersey Department of Human Services  
7 Quakerbridge Plaza, PO Box 712  
Trenton, NJ 08625-0712  
Phone: (609) 588-2600  
NAMD Region: IV

**New Mexico**
Julie Weinberg  
*Director*  
Medical Assistance Division  
New Mexico Department of Human Services  
PO Box 2348  
Santa Fe, NM 87504-2348  
Phone: (505) 827-6253  
NAMD Region: III

**New York**
Jason Helgerson  
*Medicaid Director, Deputy Commissioner*  
New York Department of Health  
Empire State Plaza, Corning Tower, Room 1466  
Albany, NY 12237  
Phone: (518) 474-3018  
NAMD Region: IV

**North Dakota**
Julie Schwab  
*Director of Medical Services Division*  
North Dakota Department of Human Services  
600 E. Boulevard Avenue, Dept. 325  
Bismarck, ND 58505-0250  
Phone: (701) 328-1603  
NAMD Region: II

**Ohio**
John McCarthy  
*Medicaid Director*  
Ohio Department of Medicaid  
50 West Town Street, 4th Floor  
Columbus, OH 43215  
Phone: (614) 466-4443  
NAMD Region: II

**Oklahoma**
Garth Splinter, MD  
*Medicaid Director*  
Oklahoma Health Care Authority  
4345 N. Lincoln Blvd.  
Oklahoma City, OK 73105  
Phone: (405) 522-7365  
NAMD Region: III

**Oregon**
Judy Mohr Peterson  
*Medicaid Director*  
Oregon Health Authority  
500 Summer Street, NE E49  
Salem, OR 97301  
Phone: (503) 945-5768  
NAMD Region: I

As of August 25, 2014
Pennsylvania
Leesa M. Allen
Executive Medicaid Director
Pennsylvania Department of Public Welfare
Office of the Secretary
331 Health & Welfare Building
Harrisburg, PA 17120
Phone: (717) 787-2600
NAMD Region: IV

Texas
Kay Ghahremani
Associate Commissioner for Medicaid/CHIP
Texas Health and Human Services Commission
11209 Metric Blvd, Building H, PO Box 85200
Austin, TX 78758
Phone: (512) 491-1339
NAMD Region: III

Rhode Island
Deidre Gifford
Director of Policy and Innovation
Executive Office
Rhode Island Health and Human Services
600 New London Avenue
Cranston, RI 02920
Phone: (401) 462-3575
NAMD Region: IV

Utah
Michael Hales
Deputy Director
Utah Department of Health
PO Box 143101
Salt Lake City, UT 84114
Phone: (801) 538-6689
NAMD Region: I

South Carolina
Tony Keck
Director
South Carolina Department of Health & Human Services
1801 Main Street, PO Box 8206
Columbia, SC 29201-8206
Phone: (803) 898-2504
NAMD Region: III

Vermont
Mark Larson
Commissioner
Vermont Department of Vermont Health Access
312 Hurricane Lane, Suite 201
Williston, VT 05495
Phone: (802) 879-5901
NAMD Region: IV

South Dakota
Kirby Stone
Division Director, Medical Services
South Dakota Department of Social Services
700 Governors Drive, Kneip Building
Pierre, SD 57501-2291
Phone: (605) 773-3495
NAMD Region: II

Virginia
Cynthia B. Jones
Director
Virginia Department of Medical Assistance Services
600 East Broad Street, Suite 1300
Richmond, VA 23219
Phone: (804) 786-8099
NAMD Region: IV

Tennessee
Darin Gordon
Director, Bureau of TennCare
Deputy Commissioner
Tennessee Department of Finance and Administration
310 Great Circle Road
Nashville, TN 37243
Phone: (615) 507-6443
NAMD Region: III

Washington
MaryAnne Lindeblad
Director
Washington Health Care Authority
626 8th Avenue, PO Box 45502
Olympia, WA 98504-5050
Phone: (360) 725-1040
NAMD Region: I

As of August 25, 2014
West Virginia
Cynthia Beane
Acting Commissioner, Bureau of Medical Services
West Virginia Department of Health and Human Resources
350 Capitol Street, Room 251
Charleston, WV 25301-3706
Phone: (304) 558-1700
NAMD Region: IV

Wisconsin
Brett Davis
Medicaid Director
Wisconsin Department of Health Services
1 West Wilson Street, Room 350, PO Box 309
Madison, WI 53701-0309
Phone: (608) 266-1271
NAMD Region: II

Wyoming
Teri Green
State Medicaid Agent
Wyoming Department of Health
6101 Yellowstone Road, Suite 210
Cheyenne, WY 82009
Phone: (307) 777-7531
NAMD Region: I

Territories
Sandra King Young
Medicaid Director
American Samoa Government
Medicaid State Agency
Pago Pago, AS 96799
Phone: (684) 633-4818
NAMD Region: Territory

Theresa Arcangel
Administrator
Guam Department of Public Health and Social Services
123 Chalan Kareta
Mangilao, GU 96913-6304
Phone: (671) 735-7282
NAMD Region: Territory

Helen Sablan
Medicaid Administrator
Commonwealth of the Northern Mariana Islands (CM)
PO Box 409CK
Saipan, CM 96950
Phone: (670) 664-4884
NAMD Region: Territory

Ricardo A. Colón-Padilla
Executive Director
PR Medicaid Program
Puerto Rico Department of Health
PO Box 70184
San Juan, PR 00936
Phone: (787) 765-2929 ext. 6700
NAMD Region: Territory

Renée Joseph-Rhymer
Director
Virgin Islands Bureau of Health Insurance & Medical Assistance
3730 Estate Altona, Suite 302
St. Thomas, USVI 00802
Phone: (340) 774-4624
NAMD Region: Territory