



THE NEW EVENT FORMAT INTENSIVES

MASTERING WHAT'S NEXT IN PATIENT AND FAMILY CARE

DIPLOMAT RESORT AND SPA | HOLLYWOOD, FL

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Making the Case: Creating a Community of
Meaningful Coalitions and Partnerships to Reach our
Goals and Measure our Outcomes

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Disclosures

- The presenters have no relevant financial relationships to disclose.



Learning Objectives

- Explain the role and reach of statewide, regional and national pediatric palliative care coalitions
- Describe two best practice models for coalitions sustainability
- Identify five action steps for creating meaningful coalitions and partnerships to enhance pediatric palliative care awareness and access.



What is a Coalition?

- *A group of people, groups, or countries who have joined together for a common purpose*
-Merriam-Webster dictionary
- *An alliance for combined action*
- Oxford Dictionary



The Power of Coalitions

Opportunities to:

- Educate – Healthcare Professionals, Families, Communities
- Advocate – Local, Regional, State and Federal
- Innovate – Develop programming, Build collaborative partnerships, Envision
- Perpetuate– Expand access to Pediatric Community and Hospital-based Palliative Care, Concurrent Care, Hospice Care, and Home Health Services



Types of Coalitions

- Independent 501c3 organizations
- Programs of existing organizations:
 - i.e. state hospice or palliative care groups
- Formal alliance of like organizations
- Informal alliance
- Loose affiliation for topical purposes
 - Education
 - Concurrent Care
 - Advance Directives



Polling Question

- My state/region has no Coalition and no known interested parties.
- We have an interested group of people, but don't know how to begin.
- We have a Coalition, but have a hard time sustaining activity.
- We have an active Coalition, but can always learn more.



Mission: Provide resources to families, volunteers and medical professionals caring for children with life-limiting illnesses.

Program Highlights: Statewide Conference, Educational Programs, Advocacy (PQLC), "The New Normal," Family Support Teams

Website: www.ppcc-pa.org

Staff:

Betsy Hawley- Executive Director

Riley Herrmann- Communications and Advocacy Coordinator



CHILDREN'S HOSPICE & PALLIATIVE CARE COALITION

Mission: Promotes high-quality, compassionate care for everyone who is seriously ill or nearing the end of life.

Program Highlights: In 2015, the Children's Hospice and Palliative Care Coalition joined the Coalition for Compassionate Care of California, consolidating CHPCC's advocacy and education efforts in pediatric hospice and palliative care as a new division of CCCC, and developed a joint public policy strategy.

Website: www.coalitionccc.org

Staff:

Devon Dabbs- Vice President, Pediatric Programming & Education



Mission: Collaborates with its members to educate, advocate for, and partner with consumers, healthcare providers and the community in order to improve and increase access to palliative care and bereavement services for children and families throughout Illinois.

Program Highlights: Membership, Mentorship, Resources, Educational Events

Website: www.gippcc.org

Staff:

Kristin James- Project Coordinator

Cathy Wilson- Administrative Assistant



Mission: Represents hospice and palliative care programs, allied organizations and individuals that are interested in the development and growth of quality, comprehensive end-of-life services.

Program Highlights: Virtual Advisor, Advocacy, Resources (“Find a Provider” website feature), 2-day Interdisciplinary Training

Website: www.hpcanyspediatricpalliativecare.org

Staff:

Center for Excellence in Pediatric Palliative Care
2 Computer Drive West, Suite 105
Albany, NY 12205

info@hpcanys.org

518-446-1483



Mission:

Program Highlights:

Website: No longer active

Staff:



Mission: We bring providers, business partners and individuals together to increase knowledge, access services and strengthen advocacy for people living with a serious illness or experiencing the end of life.

Program Highlights: Online Resources, Legislative Advocacy

Website: www.mnhpc.org/individuals/pediatric-palliative-care/ppccmn/

Contacts:

Scott Schwantes, MD

Associate Medical Director-Pediatrics

Gillette Children's Specialty Healthcare

Jody Chrastek, DNP, CHPN

Pediatric Advanced Complex Care Team Coordinator

Fairview Home Care and Hospice



Mission: Working to bring palliative care to Texas children and their families.

Program Highlights: Educational Programming, Conference, Legislative Advocacy

Website: www.texasppcc.org

Staff:

Jan Wheeler, Ed. D. - Executive Director

Contacts:

Melody Brown Hellsten DNP, RN, PCCNP, CHPPN- Chairwoman

Gina Leigh Jones RN, CPLC- Education Chairwoman



CHILDREN'S PALLIATIVE CARE COALITION of Michigan

Mission: To provide resources for medical professionals, volunteers and families caring for children with life-limiting illnesses, and to ensure the availability of compassionate, comprehensive care across the State of Michigan.

Program Highlights: Membership, Conference, Legislative Advocacy, Family Resources

Website: www.childpalliative.org

Staff:

None, run by the Executive Committee



Other PPC Coalitions:

- **Kansas Hospice and Pediatric Palliative Care Coalition**
- **Alliance Kids (Maryland)**
- **Pediatric Palliative Care Coalition of SC**
- **Georgia – loose affiliation**



Best Practices:

What makes these Coalitions successful?

- Establish priorities
- Create opportunities for incremental success
 - key to membership engagement
 - Identify specific, quantifiable goals/tasks
- Identify your partners
 - Who is on your team? Think broadly. Talk with other coalitions regarding their membership composition.
 - Don't forget families – it's really all about them!



What can coalitions accomplish?

- Sharing knowledge, skills, best practices
- Special programs
- Strength in numbers for advocacy
- What are your ideas?



Sustainability Considerations

- CREATING VALUE
 - Value to participants/members
 - Value to interested stakeholders
 - Individuals
 - Health care personnel & systems
 - Payers
 - Legislators
 - Families
 - Value to community at large



Sustainability Considerations

- Needs assessment
 - Are you responsive to the needs of your stakeholders?
- Structure
 - Independent vs alignment
 - Strong state or regional hospice/hospital system
 - 501c3 status
 - Internal organization
 - Mission, vision, bylaws/guidelines
- Staffing
 - Volunteer army vs paid staff
- Measurable outcomes



Sources of Funding

- Grants for programming/research
- Support from parent organization
- Fees for educational programming
- Membership fees
- Sponsors for conferences and events
- Event fundraising
- Community fund raising
- Sale of resources



What makes a good measure?

- Uniform
- Easy to collect
- Based on best-available evidence
- Allows comparisons across institutions, organizations, agencies, groups
- Relevant to your coalition & stakeholders



Domains of measurement

- Operational
 - Adherence to national standards
 - Core features of a high-quality program
- Clinical
 - Prospective metrics
 - Functional outcomes
 - Safety
- Customer
 - Access/Outreach/penetration to market
 - Referral satisfaction
- Financial – costs, utilization



Measuring Quality

- Structure
 - Characteristics of organization
- Process
 - Encounters between stakeholders and organization
 - Access to resources
- Outcome
 - Subsequent health status or impacts
 - Reduced suffering, improved safety



Can a coalition impact quality?

- Domains of Quality
 - Safe
 - Effective
 - Patient-centered
 - Timely
 - Efficient
 - Equitable
- Alignment with national benchmarking opportunities
 - Measuring What Matters





Outcomes measurement sample

Outcomes	Indicators	Data Collection Methods/Tools	Schedule and Frequency of Data Collection
1. Increase community awareness of pediatric palliative care	Newsletter subscriber #s	E-mail Marketing (i.e. mail chimp, constant contacts) – track # of subscribers open; # of clicks through; track retention and increase in # of new subscribers	Every 6 months
	Facebook page followers Facebook page visitors	FB page metrics	Every month
	Website	Site metrics	Every month
2. Provide information and resources to providers	Educational Programs	# of educational programs organized	Annually
	Educational Program attendance	# of attendees	Annually
3. Provide information and resources to caregivers	Resources available to families on website	# of resources published on site	Monthly
	Family page site visits	Site metrics	Monthly
	Public Events – i.e. conferences, health fairs	# attendees; # of materials distributed	Every 6 months
4. Advocate for the needs of children with serious, chronic, and life-limiting illnesses	Communications with legislators	# of emails sent # of phone calls made	Every 6 months
	Public Policy Day or legislative visits	# of visits	Annually
5. Broaden access to care for children with serious, chronic, and life-limiting illnesses	ACA Concurrent Care	# of children enrolled	Annually
	Palliative Care	Online survey; # of institutions, hospices with ppc program	Annually
6. Support our member base	Satisfaction	Online survey	Annually
	Membership	Retention and increase in membership #s	Every 6 months



Group Exercise



Polling Question

- 3 top priorities for a coalition
- Who would you bring together - at least three individuals
- 3 steps in the next three months to get this started
- What would you like to see happen in your state in the next year, in two years, in five years?
- Identify 3 barriers to coalition formation



Expanding our view

- Is there a benefit to working nationally?
- Identify overlapping issues
- Best methods for national collaboration



The Power of Coalitions

We are **UNIFIERS**, able to bring together the diverse perspectives of families, hospitals, local providers, payers, communities, churches and other stakeholders towards a common vision.

We are **REVOLUTIONARIES**, speaking out on behalf of those too little or too sick to speak for themselves.

We are **ADVOCATES**, challenging the existing healthcare system for children with life-threatening conditions and insisting that public funding for healthcare services be in alignment with their unique needs.

We are **PARTNERS**, aligned with and inspired by one another. Together we are stronger. Together we will succeed.



Stay in Touch

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