Akron Children’s Hospital’s
Comprehensive Pediatric Palliative Care Program

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11:00 – 12:00 ET
Akron Children’s Hospital (ACH)

- Free-standing 3rd/4th care children’s hospital
  - Established in 1890
- 353 beds (2+ campuses)
  - Care for more than 600K patients/year
- Only children’s hospital in area
  - Large amount of community support
  - NICUs in 2 adult hospitals
- Regional burn center (adult + pediatrics)
- Affiliated home care agency
- Network of “satellite” primary care offices
Pediatric Palliative Care at ACH

- Academic Division of Pediatrics since 2002
- Any age with pediatric diagnosis or specialist
- Any complex, chronic +/- life-threatening condition
- Hospital-based team available 24/7/365
  - Inpatient consultation
  - Inpatient primary medical service
  - Multiple clinical, research, education, and advocacy initiatives
  - Outpatient services designed to fit family
    - Collaboration with PCP
    - Coordination with local/regional home care and hospice
Our Palette Mission

• To integrate legendary and indispensable pediatric palliative care into the journey for all children facing chronic, complex and/or life-threatening conditions and their families

• To provide leadership in education, research, and advocacy initiatives in pediatric palliative care locally, regionally and nationally
Definition of Pediatric PC

- Organized method of delivering holistic, transdisciplinary care to children with chronic, complex and/or life-threatening conditions & their families

- Holistic: physical /medical, psychological /emotional, social, spiritual, practical, developmental/cognitive, educational/vocational

- Provided **concurrently** with disease-directed, cure-directed, life-prolonging therapy
Palliative Care for children...

- Seeks to prevent or relieve symptoms produced by a life-threatening medical condition or its treatment
  - Aggressive symptom management
- Offers help for children with such conditions and their families to live as normally as possible
  - Holistic care focused on domains of suffering
- Provides families with timely and accurate information and support in decision making
- Provides support for caregivers

IOM 2003
Anticipatory Guidance

• PREVENTION
• Medical home model
• Like immunization against crisis-driven, desperate, expensive decision making
• Providing partnered/shared decision making for families facing life-threatening conditions
  – True meaning of “family-centered care”
• Families/providers make better, more informed decisions
  – Decreases decisional regret
• Lessens collateral damage for all
Center Statistics

• Since 7/02:
  – 1700+ patients/families enrolled
  – 52 counties represented, + 8 other states
  – 60% Medicaid or Medicaid HMO
  – 56% male, 44% female
  – 76% Caucasian, 16% AA, 6% Amish
Diagnoses Served (2002-2011)

- Neurologic: 29.7%
- Hematologic/Oncologic: 17.8%
- Cardiologic: 9.9%
- Genetic: 9.3%
- Sudden/Burn: 9.2%
- Pulmonary: 4.8%
- Musculoskeletal: 4.5%
- Complex Chronic: 3.3%
- Renal: 2.9%
- Metabolic/Endocrine: 2.4%
- Gastrointestinal: 2.2%
- In Utero/Prematurity: 2.1%
- Infectious Disease: 1.9%

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Referral Criteria: Triggers

- In the field: [www.capc.org](http://www.capc.org)
- In Akron:
  - Complex congenital heart disease diagnosis
  - BMT admission – pain management
  - In ICU > 1 week
  - Neurodegenerative: SMA-1, Muscular dystrophy
  - Cancer with poor prognosis or tough journey
  - In utero diagnosis of severe anomaly
  - Chronic kidney disease
  - Severe CF or at lung transplant discussion
  - Technology-dependent (tracheostomy, vent-dependent)
  - Significant pain/non-pain symptom management need
  - Limitation of intervention orders (AND)
  - Select NICU patients
Age Breakdown (2002-2011)

- <1 yr: 37.1%
- 1-10 yrs: 26.2%
- 11-15 yrs: 12.7%
- 16-20 yrs: 13.9%
- >20 yrs: 10.1%
Referral Source (2002-2011)

- PICU: 28.8%
- *Subspecialty Care: 6.0%
- NICU: 6.3%
- Outside Agencies/Therapies: 7.0%
- *Surgery: 9.0%
- FTC/MFM: 11.1%
- General Medical: 27.8%
- Parent/Family: 2.8%
- Transport/ER: 1.2%
- PC/Hospitalist/Genetics/MD Clinic: 0.8%
ONE BENCHMARK FOR ACCESS

% of Hospital Deaths with PC Involvement

0% 10% 20% 30% 40% 50% 60% 70% 80% 90%

2002 2003 2004 2005 2006 2007 2008 2009 2010
What it’s really all about

• COMMUNICATION
• COMPASSION
• COORDINATION
• COLLABORATION
• ACCESS
• EASING SUFFERING
• MEETING A FAMILY WHERE THEY ARE AND WALKING A JOURNEY THROUGH THE FOREST
• BEING ABLE TO GET UP IN THE MORNING AND DO IT ALL OVER AGAIN
Pediatric Palliative Care – Relationships

• Patients and families
• Intra-team
• Internal to institution/enterprise
  – Referring clinicians and peers
  – Administration
  – Development/Marketing
• External
  – Community & allied health orgs/resources/agencies
  – Universities/educational institutions
  – Philanthropic organizations/supports
  – Media
Referral Sources

• In-hospital
  – PICU, subspecialty services
  – Fetal Treatment Center

• External to institution
  – PCPs
  – Home care agency
  – Long-term care facility
  – County Boards of DD/Early Intervention
  – Therapies, schools

• Parents/families
Value Adds

- Home visits
- 24/7 availability
- Prenatal consultation
- Case management
- Financial assistance
  - Gift cards, gas cards, phones, transportation, funeral expenses, mortgages, utilities, unplanned expenses
- School interventions/IEPs
- Support groups, including siblings
- Individual counseling
- Spiritual support
- Memory making
- Bereavement care as long as desired
- Education *everywhere*
- Advocacy – local, state, national
The Palette Concept: Painting a canvas
Questions?

Comments?
Pediatric Palliative Care – Training Program

- ACGME-accredited physician fellowship
- ELNEC-based program for nurses
- Pediatric Palliative Care Curriculum
- Training site for multiple disciplines
- Development of local/national curricula
Pediatric Palliative Care Financials

• Rule of Thirds
  – Billing revenue
    • Case mix, team composition, APN billing, billing system effectiveness, team efficiency, # visits
    • Proportion of Medicaid
  – Departments, hospital, community partners
    • Supports programming, education, core services
    • Includes hospice contracts
  – Philanthropy, grants
    • Value-added services, not people

• Assumption: service mix
Value Propositions

- Reduced readmissions
- Actual cost of care
- Decreasing LOS
- Throughput issues
- Increased pt/family satisfaction leading to downstream referrals
- Community Benefit/relationships
- Staff satisfaction/provider efficiency → RETENTION
- 24/7 availability
- Reduced liability for iatrogenic harm
  - Line infections, c diff, MRSA, etc.
- Reduced malpractice liability/risk of lawsuits
- Extends utilization/productivity of other providers
Center Staff – Colors on the Palette

2.85 FTE Physicians
2 Nurse Practitioners
1 Case Manager/Clinical Nurse Specialist
0.7 Chaplain
2 Social Workers
1 Bereavement Coordinator (SW)
2 Palliative Care Fellows (3rd in 2012-13)
2 Administrative Assistants
1 Research Assistant
0.2 Psychologist
2 Expressive Therapists (1 Art, 1 Music) + Coordinator
Contracted: PT, OT, Dietitian, Child Life Specialist, Massage Therapist
Support Staff: Home care nurse supervisor, learners, photographer, volunteers (including in-home)
Care Coordination Staff for CMMI
Center Highlights

- Winner of AHA Circle of Life Award 2012
- Convener of state-wide PPC consortium (OPPEN)
- Hosted national conference in 2007
- ACGME-accredited fellowship training
- CAPC national Leadership Center training site
- Designated as service coordination site for state Title V program (BCMH)
- Winner of Children’s Miracle Network Award
- Endowed chair established
- Expressive Therapy Center, Healing Garden
- Palette of Faith and Respecting Options of Care
Questions?

Comments?
ACH: NEXT STEPS

• Joint Commission accreditation
• Focus on team health
• Expanded research agenda
  – Impacts on quality and safety
• Centers for Medicare and Medicaid Innovation Award
  – Population health management
  – Episodic/bundled care
ACH: ADVICE FOR OTHERS

• Align mission with organization
• Measure early and often
• Get in early with billing folks
• Work closely with Marketing/PR
  – “Yes, when and where?”
• Embed within Development
• Cultural change is slow: Be patient!
• THANK YOU!

• Sarah Friebert, MD
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