

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 3^o/4^o 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 + peds)
- 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

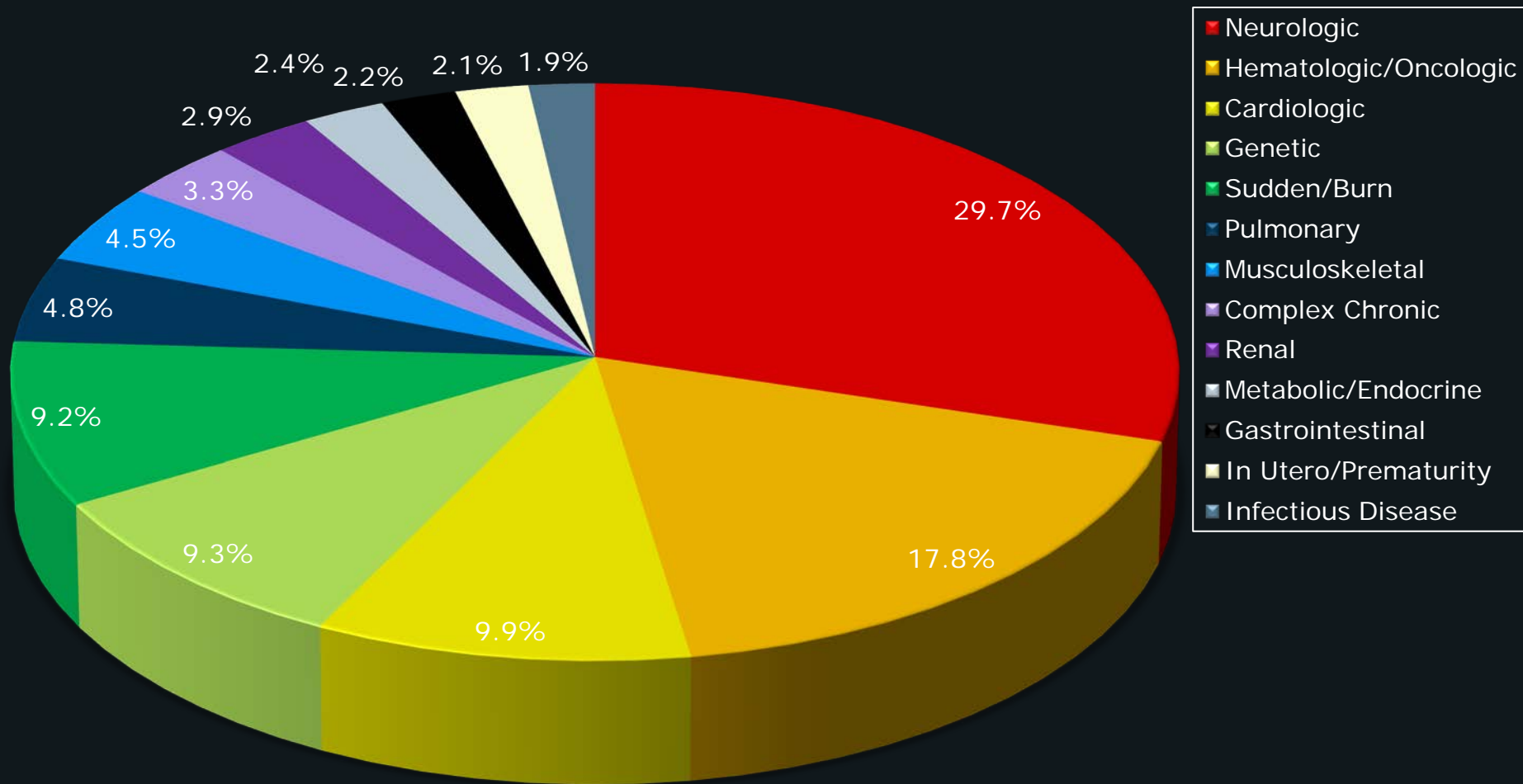
- PREVENTION
- Medical home model
- Like immunization against crisis-driven, desperate, expensive decision making
- Providing partnered/shared decision making for families facing life-threatening conditions
 - True meaning of “family-centered care”
- Families/providers make better, more informed decisions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

Center Statistics

THE
HASLINGER FAMILY
PEDIATRIC
PALLIATIVE
CARE CENTER

- 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

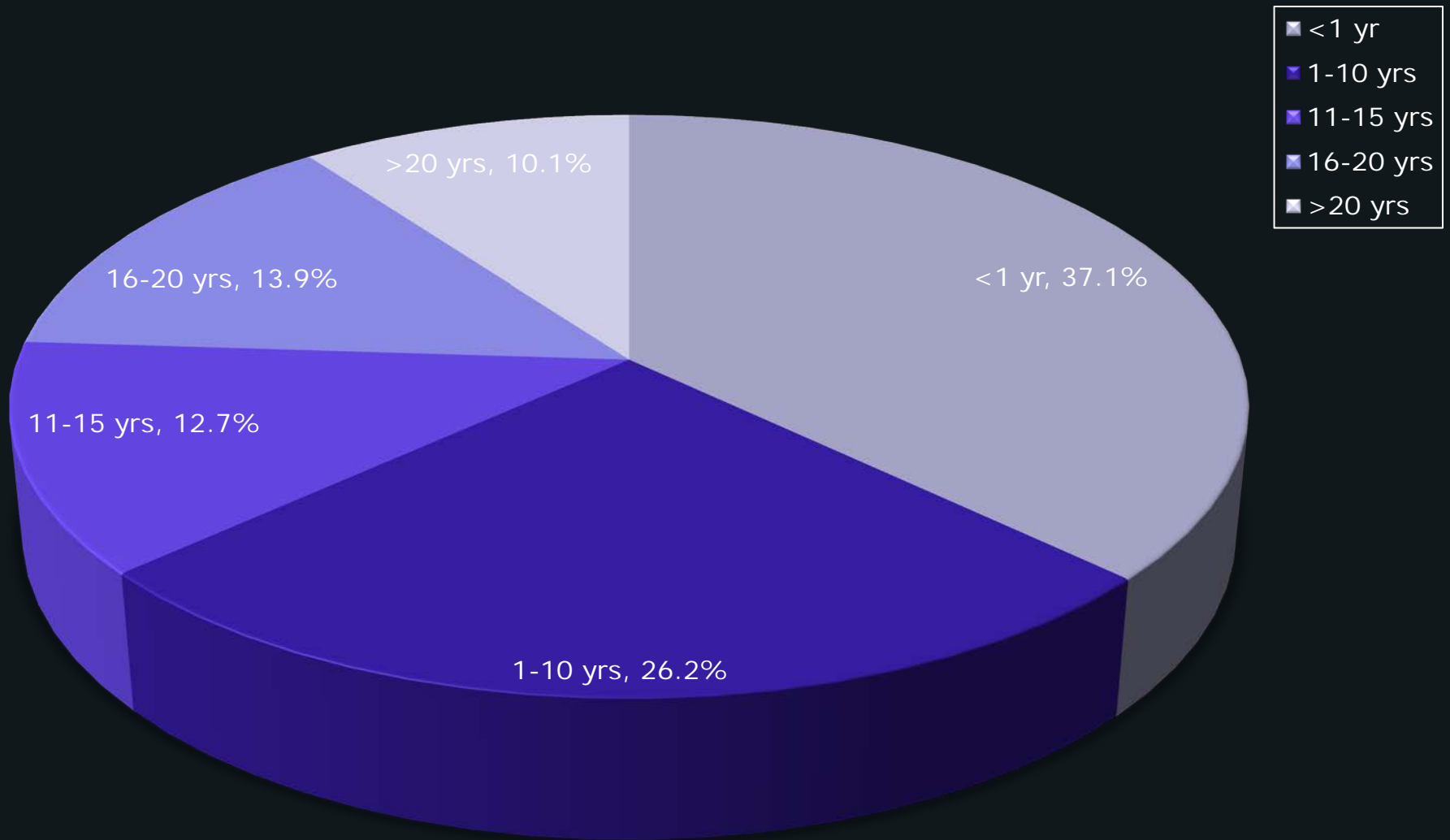
Diagnoses Served (2002-2011)



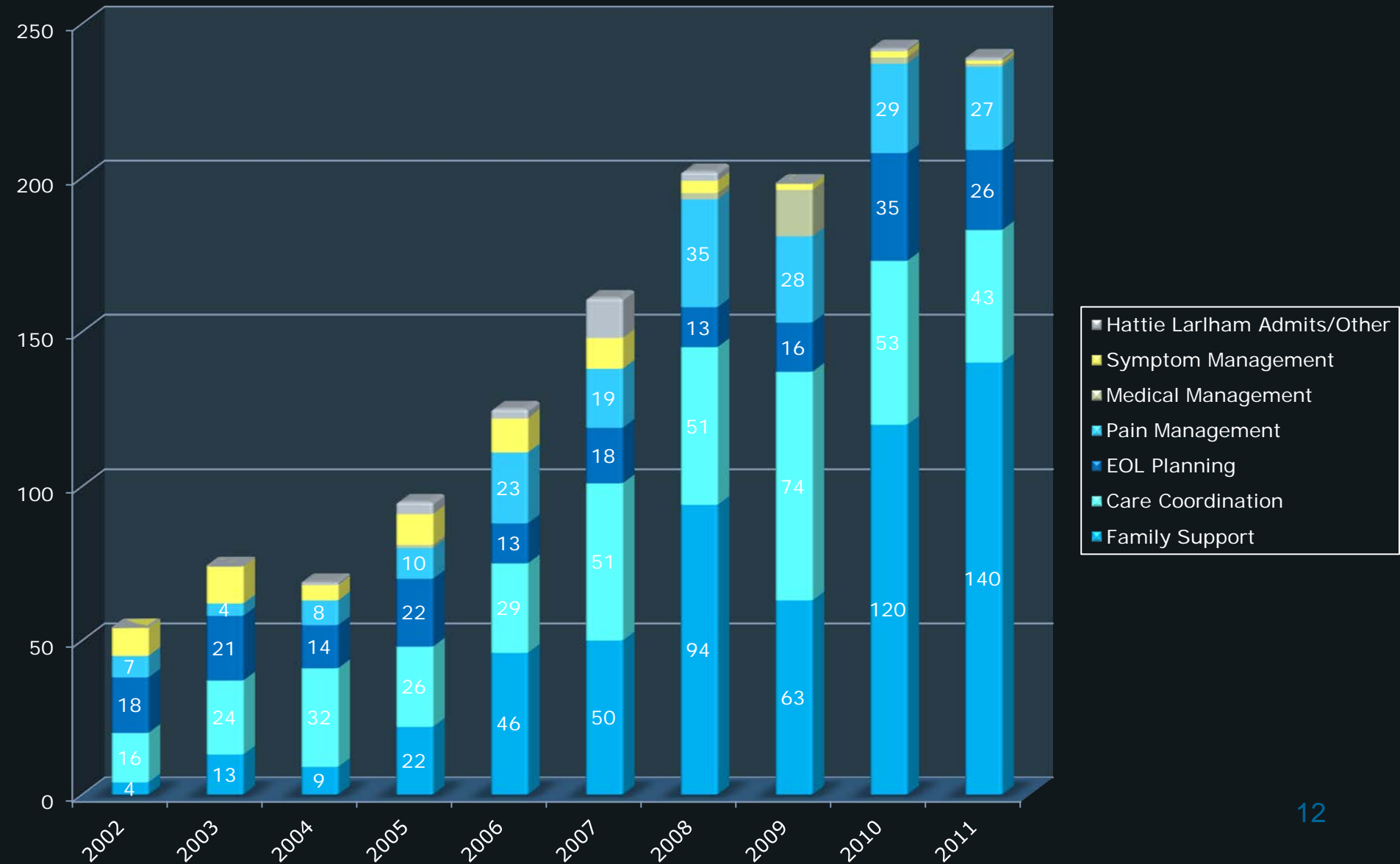
Referral Criteria: Triggers

- In the field: 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

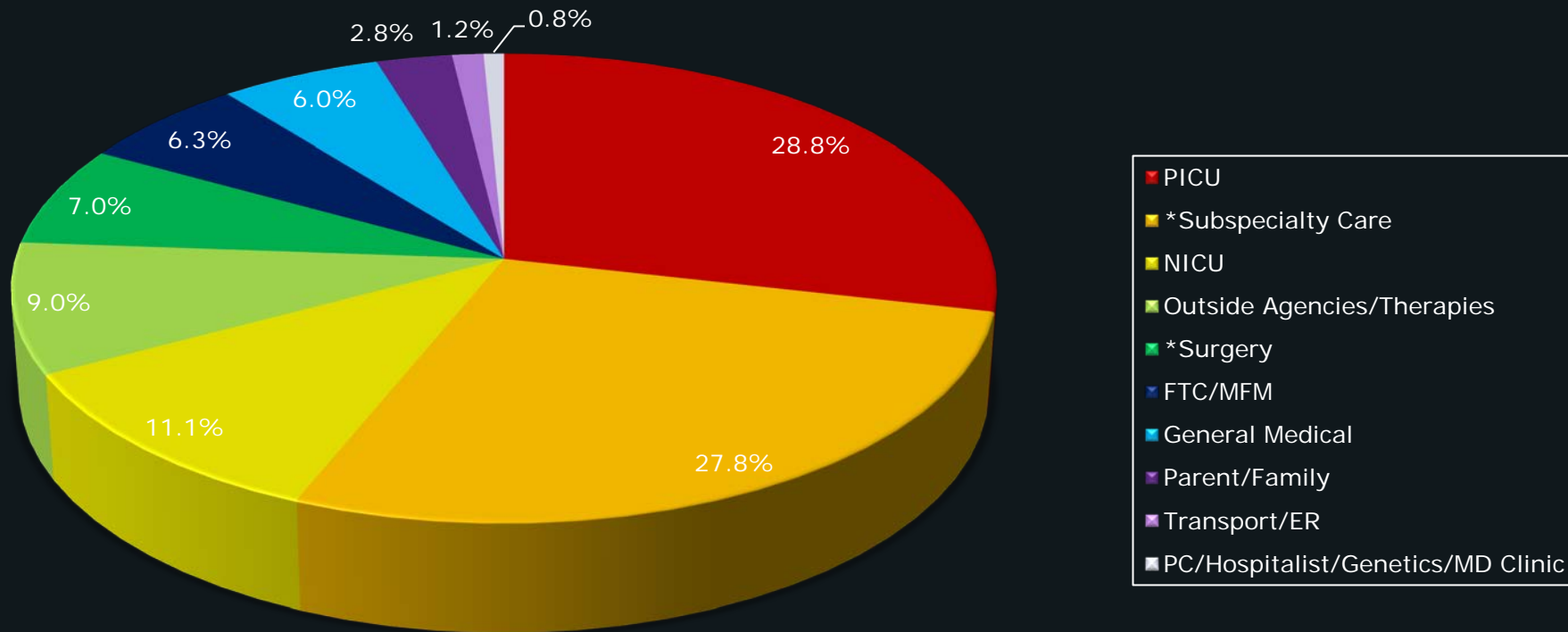
Age Breakdown (2002-2011)



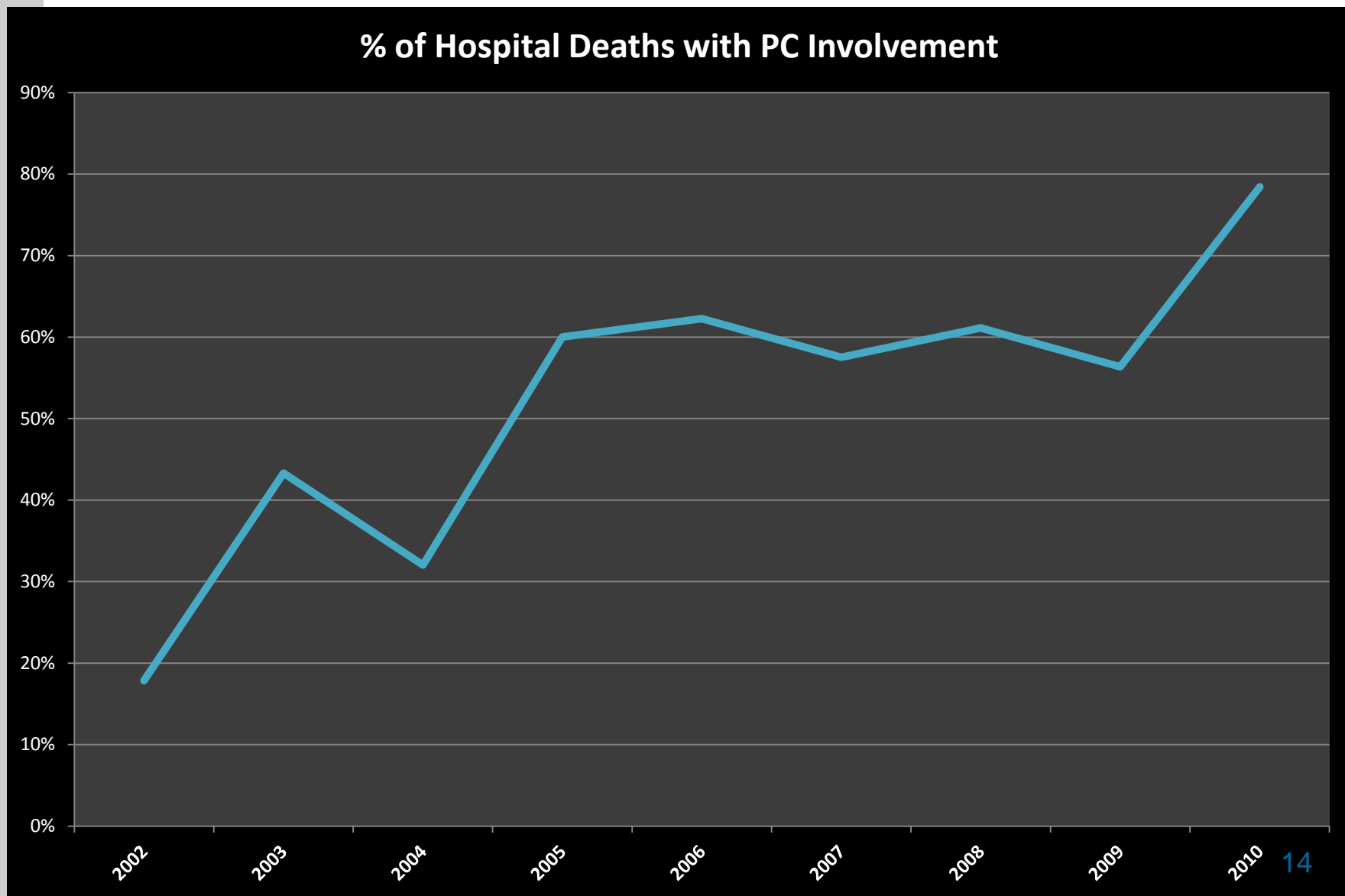
Types of Referrals by Year



Referral Source (2002-2011)



ONE BENCHMARK FOR ACCESS



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

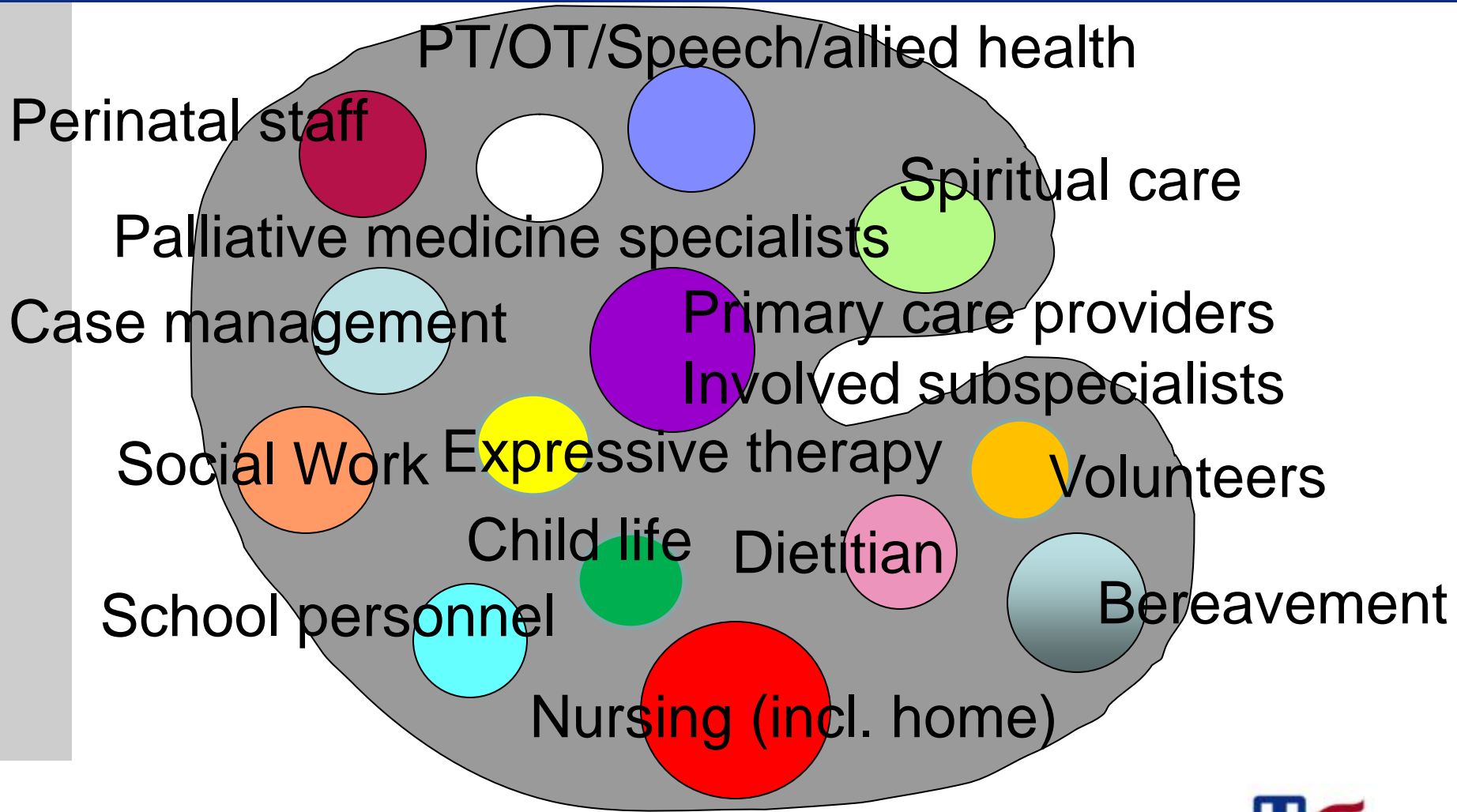
Referral Sources

- 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!



MOVING FORWARD

- THANK YOU!
- Sarah Friebert, MD
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