

Development of Sarah House, a Children’s Hospice Home in Ohio to Fill the Gap in Unmet Overnight Respite and Pediatric Palliative Care Needs

Most of the 129,313 babies born in Ohio during 2020 will enjoy normal, typical lives. Sadly, about 1% of these children will experience chronic, complex medical conditions that shorten their life expectancy and prevent them from reaching adulthood. Parents always hope for a cure. Some children will survive with effective medical treatments. Also in 2020, 1,026 children under 19 years old died of natural causes in Ohio.¹

Problem:

Children with complicated, chronic, and/or life-limiting illness place heavy demands on family members. Despite becoming expert caretakers, parents are often taxed beyond their ability to cope well, balancing spousal demands, work schedules, and parenting duties of other children. In the U.S., there are approximately 2.1 million children with medical complexities (CMC)², and according to the CDC, over 40,000 children under 19 years old died in 2019. A 2020 published systematic literature review of family experiences with palliative care for children at home noted that “respite care was needed in order to cope with everyday life.”³ “Respite is a gift” is a common theme expressed by parents because of the continuous caring required for their child throughout the day and night.^{4 5} While the family home may be a suitable environment for these children, competing forces increase pressure on family caregivers and raise the critical need for supplementary out-of-home solutions. These challenges include pediatric home health nurse shortages⁶, longer lives of CMC due to medical advances, and insufficient insurance reimbursement.

Solution:

Established in 1982 in Oxford, England, [Helen House](#) began the global Children’s Hospice Home movement. Children’s Hospice Homes assist families whose children have a recognized shortened life expectancy. Ideally, a family connects with a Home team upon discovering their child has a life-limiting condition, often at diagnosis. At no cost, the family is provided much-needed overnight respite, palliative care, and end-of-life hospice services when needed. Although globally referred to as a “Hospice Home,” typically less than 20% of the services are actually for end-of-life care. The majority (80%+) is often providing planned overnight respite for CMC and their families. The Home’s “shared services” model offers lower costs than one-to-one homecare, with one or two nurses overseeing up to eight children supported by volunteers and attendants. For staff, it is often “a calling,” which minimizes turnover and strengthens team continuity. These Homes function as neither a hospital nor a daycare. Instead, they become an extension of home, fulfilling the missing respite gap in a typical care continuum.

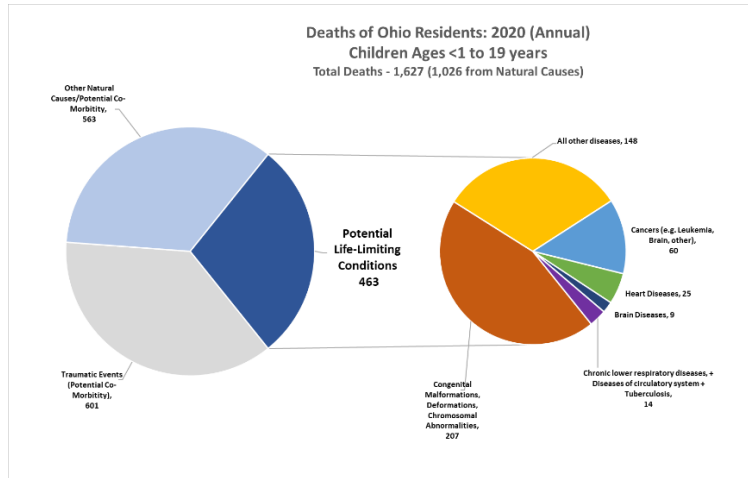
Issue:

Despite being 1/5 the size of the U.S., the U.K. is recognized as a global leader in pediatric palliative and hospice care. Twenty years ago, about 42 Homes existed in the U.K.; now, the number is 54. Adjusting for population and size, the equivalent number of U.S. Homes would be 266—yet there are only three; “[GeorgeMark Children’s House](#)” (opened 2004), “[Ryan House](#)” (opened 2010), and “[Crescent Cove](#)” (opened 2018). Despite having served over 10,000 families cumulatively, these Home concepts are just appearing on the U.S.’s radar screen. Ohio’s expertise is recognized with 2 of the Top-10 Children’s Medical Centers in the U.S., yet there are no free-standing Children’s Hospice Homes dedicated to supporting this population with overnight respite, palliative care, and when needed end-of-life care within its borders. But momentum is building.

Opportunity:

Sarah House (aka Sarah Zepernick Foundation), a 501(c)3, incorporated in 2007 to create Ohio’s first Children’s Hospice Home care model. The leadership team at Sarah House is actively participating in a national coalition with the three existing U.S. Homes, and another 15+ emerging communities to share learnings and scale best practices. While the original Homes opened primarily through philanthropic support, recent operations have succeeded in securing a portion of expenses through important Medicaid reimbursement which will ease ongoing sustainability of this model. A renewed Sarah House Board has recently added five new members in 2021, and is actively developing its strategic plan to formalize a capital campaign

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Deaths of Ohio Residents: 2020

Age	≤1	1 to 4	5 to 9	10 to 14	15 to 19	Total
Potential Life-Limiting Qualifying						
Congenital Malformations, Deformations, Chromosomal Abnormalities						
	173	15	1	9	9	207
All other diseases						
	54	21	16	22	35	148
Cancers (e.g. Leukemia, Brain, other)						
	2	16	10	19	13	60
Heart Diseases						
	12	2	2	0	9	25
Brain Diseases						
	1	1	1	2	4	9
Chronic lower respiratory diseases, + Diseases of circulatory system + Tuberculosis						
	0	4	2	2	6	14
= Potential Life-Limiting Conditions						
	242	59	32	54	76	463
Typically Non Qualifying (Potential Co-Morbidity)						
Certain conditions originating in the perinatal period						
	423	1	0	0	0	424
Sudden infant death syndrome (SIDs)						
	67	0	0	0	0	67
Symptoms, signs and abnormal clinical and lab findings not elsewhere classified						
	30	3	1	1	2	37
Influenza/Pneumonia						
	9	5	1	5	1	21
Diabetes						
	0	0	1	2	6	9
Nephritis related (Kidney)						
	4	0	0	0	1	5
Other Natural Causes/ Potential Co-Morbidity						
	533	9	3	8	10	563
= SUBTOTAL NATURAL CAUSES OF DEATH						
	775	68	35	62	86	1026
Traumatic Events (Potential Co-Morbidity)						
All Other and unspecified accidents and adverse effects						
	69	39	16	13	72	209
Homicide						
	12	15	7	19	111	164
Motor Vehicle accidents						
	3	13	11	19	75	121
Suicide						
	0	0	0	26	64	90
All other external causes						
	5	3	1	1	7	17
= Traumatic Events						
	89	70	35	78	329	601
Total Deaths						
	864	138	70	140	415	1627

Ohio Department of Health; Vital Statistics, 2020 Preliminary Data. Accessed 1/21/22
 Source: <https://publicapps.odh.ohio.gov/EDW/DataBrowser/Browse/Mortality>

References:

1. Ohio Department of Health; Vital Statistics, 2020 Preliminary Data. Accessed 1/21/22. <https://publicapps.odh.ohio.gov/EDW/DataBrowser/Browse/Mortality>
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3. Winger A, Kvarme LG, Løyland B, Kristiansen C, Helseth S, Ravn IH. Family experiences with palliative care for children at home: A systematic literature review. *BMC Palliat Care*. 2020;19(1):165-4. doi: 10.1186/s12904-020-00672-4 [doi].
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6. Weaver MS, Wichman B, Bace S, et al. Measuring the impact of the home health nursing shortage on family caregivers of children receiving palliative care. *J Hosp Palliat Nurs*. 2018;20(3):260-265. doi: 10.1097/NJH.0000000000000436 [doi].

Existing U.S. Children’s Hospice Homes:

GeorgeMark Children’s House (San Leandro, CA)
<https://georgemark.org/>

Ryan House (Phoenix, AZ)
<https://ryanhouse.org/>

Crescent Cove (Brooklyn Center, MN)
<https://crescentcove.org/>

Respite Only:

A Rosie Place (South Bend, IN)
<https://arosieplace.org/>

Included in Emerging Coalition:

Sarah House (Cincinnati, OH)
<https://www.sarahhousecincy.org/>

LadyBug House (Seattle, WA)
<https://www.ladybughouse.org/>

Life House Atlanta (Atlanta, GA)
<https://lifehouseatlanta.org/>

Hero’s Path Palliative Care (Albuquerque, NM)
<https://www.herospathpalliativecare.org/>

Here 4 U (Farmington Hills, MI)
<http://www.here4u.net/>

Angel’s Place (New Orleans, LA)
<https://www.angelsplacenaola.org/>

Rays for Rare / Lucas House (Idaho)
<https://www.raysforrare.org/> <https://www.raysforrare.org/>

The Pinwheel Project (New York, NY)
<https://www.thepinwheelproject.org>

+ Many more in various stages of development