

New Community Circle Of Life Provides Pediatric Palliative Care



Imagine having a child who gets a devastating medical diagnosis. Would you know where to turn for support? To help make the situation easier, New Community has partnered with Circle of Life, which provides pediatric palliative care and clinical services for children with life-limiting illnesses.

Circle of Life, which has been in operation for nearly two decades, became an affiliate of New Community Corporation this past summer. Dr. James Oleske founded Circle of Life and remains as its medical director. He has known New Community Founder Monsignor William J. Linder his whole career and honored him at past Circle of Life events.

The two began talking about the future of Circle of Life. "We both agreed that Circle of Life really needed a nonprofit program along with another larger program that could ensure its continued services for children and families in Newark," Oleske said.

After logistics were worked out, the affiliation became official in July 2017.

"It's an honor for me," Linder said about teaming up with Oleske. "I love working with him. He's a gem of a human being. If everyone was like him, the world would be such a better place."

Oleske first began providing palliative care after taking care of children with AIDS.

"Early in the epidemic, most died. I went to a lot of funerals. I got to understand the importance of talking to families of children with life-limiting and life-threatening illnesses," Oleske said. "I understood the importance of end-of-life care. I decided 18 years ago there should be a formal program to train people to provide these services."

Oleske found that palliative care programs for children were rare and when they did exist, they were more likely in affluent areas for children with cancer.

"Circle of Life was born out of what I saw was a need 18 years ago for palliative end-of-life care for children and families in this area," Oleske said.

The endeavor wasn't easy. End-of-life care, particularly for children, isn't a subject many people want to think about or discuss. Government funding is also scarce.

Dr. Onajovwe Fofah serves as the associate director of Circle of Life and is the medical director of the Neonatal Intensive Care Unit and Newborn Services at University Hospital. He became involved in the program in 2006, but has known Oleske since 1992 when he was a resident.

"I work with Dr. Oleske to help to develop programs and identify families as well as sit on the board of Circle of Life," Fofah said. "The bulk of my services are through program development."

Circle of Life is a three phase program meant to serve the child and family through the most critical stages of illness.

The first six months of the program is Phase One: Critical Care. That involves inpatient and outpatient palliative care services for children with specialized palliative care in the home, utilizing skilled and experienced pediatric nurses, social workers and other professionals.

Phase Two occurs from six to nine months in the program and is called Outpatient Clinical Services. This phase offers supportive palliative care services to provide family mentoring.

The final phase is Self Sufficiency and occurs from nine to 12 months into the program. Phase Three offers outpatient services, which includes support groups and mentoring.

Fofah relayed a story of a family helped by Circle of Life early in his involvement. An immigrant from Senegal in Africa was found to be carrying a child with an extra chromosome. Babies typically die before their first birthday with the condition. After the baby was born, Circle of Life got involved.

"Just before discharge, the mother said to us, 'I would love for my baby to be taken to Africa so she can die in my village with my mother.' With help of this program, we arranged with the airlines and the baby went home to Senegal. She died surrounded by people of the village," he said.

Circle of Life also helps when a child dies with funeral arrangements. For women with stillborn babies the program may also provide memory boxes to help with the grieving process.

"Then after [the funeral] continue to follow her, walk through the process of grief and bereavement with her so she's not left alone," Fofah said. "That holistic approach to grief and grief recovery is what this program is about."

Fofah is optimistic about the future for Circle of Life. "My hope is that it will be incorporated into care as part of the routine prenatal, perinatal and neonatal and pediatric care," he said.

Linder hopes to grow Circle of Life to serve more people. "It's a program that parents need," he said. "They need a support system when they lose a child or are going to lose a child."

For more information about Circle of Life, visit www.newcommunity.org/new-community-circle-of-life or call or text 973-317-8549.