

The Children's Mercy Beacon Program For Children With The Most Complex Special Needs

The Children's Mercy Beacon Program provides a patient-centered primary care medical home for children with the most complex special needs, as well as for their siblings.

The Beacon team communicates with health care providers in clinics, hospitals, schools and at home to coordinate care and assist with transition throughout the health care system.

The program streamlines the health care process for families with at least one child with medical complexity, from birth to 21 years, and their siblings.

Amber Hoffman, MD is here to discuss how care is coordinated across multiple specialties to simplify appointment scheduling and to reduce patient visits and inpatient admissions.



Featured Speaker:

Amber Hoffman, MD

Amber Hoffman, MD, is the Medical Director of the Beacon Program, which provides a medical home for hundreds of children of medically complex conditions. Dr. Hoffman received her medical degree from the University of Pittsburgh School of Medicine and completed a residency in pediatrics at Children's Hospital of Pittsburgh. She has special interests in residency education, diagnostic dilemmas and helping children with special health care needs.

[Learn more about Amber Hoffman, MD](#)

[http://www.childrensmercy.org/Clinics and Services/Clinics and Departments/doc=11043](http://www.childrensmercy.org/Clinics_and_Services/Clinics_and_Departments/doc=11043)



Transcription:

Dr. Michael Smith (Host): Welcome to *Transformational Pediatrics*. I'm Dr. Michael Smith and our topic is "The Beacon Program: A Medical Home for Children with Medical Complexity." My guest is Dr. Amber Hoffman. Dr. Hoffman is the Medical Director of The Beacon Program. Dr. Hoffman, welcome to the show.

Dr. Amber Hoffman (Guest): Thank you for having me on.

Dr. Smith: Tell us about the Beacon Program; how it got started, even how you got started in it and what are the goals of the program?

Dr. Hoffman: The Beacon Program was created officially in October of 2013. I had had a sense that the children of Kansas City really needed to have a place where they could have comprehensive care for those children that really didn't fit into one subspecialty. I would see patients on the in-patient world and say to myself, "If I could just get my hands on you out-patient I think that I could really help you." I

got together with my co-director Ingrid Larson, who is a nurse practitioner, and together we really came up with a vision of creating a better life for children with medical complexity for both them and their families in the Kansas City region. Our program is a medical home for kids who really are at that top level of complexity. The vast majority of our children have very complex problems: cerebral palsy, neurodegenerative diseases, neuromuscular diseases, complex cardiac or pulmonary diseases. The vast majority have some type of mechanical device, whether it's a feeding tube, a tracheostomy, a ventilator, a vagal nerve stimulator, and a lot of outpatient needs such as needing help with all activities of daily living: wheel chairs and lots of physical therapy. We've also worked into our patient population and enrolling patients into this program those with really significant social concerns such as extreme poverty, living in foster care, having language or cultural barriers and cognitive impairment of caregivers. We wanted to create a sort of a beacon – which is where our name came from – where we could help guide families through the sea of healthcare and work with them together to really have a relationship that is focused on respect, communication, education and support to create a better life for their children.

Dr. Smith: Dr. Hoffman, when you say a “medical home” what exactly is that? Is this a foster home in some cases or is it more of like a long-term care facility? Maybe describe what the home actually is, what it looks like and what goes on there.

Dr. Hoffman: Sure. We provide primary care to our patients. So, anything from well child visits to ill visits. We have a very comprehensive visit that we do once a year called a health and services evaluation where our entire team comes together to create a care plan for that patient for the year. We have social workers, registered dietitians, nurse practitioners, nurse care coordinators, those that manage the home equipment. One of our staff members is wound care certified. We create a huge care plan for that patient throughout the year. We also create an emergency information form for them so that when they are utilizing emergency services--they're either calling 9-1-1 or showing up in an emergency department--they have a quick summary of who their child is and what their needs are and some emergency contingency plan for that child. We also take the extra step of seeing our patients when they get admitted to the hospital so that their care plan continues on the in-patient realm and we can help that team that is taking care of them in the in-patient world not start over from the very beginning but rather move forward in a way that makes sense for that patient. We are just starting our telemedicine visits at this point where we will be doing not only co-management of patients that live remote from our institution but also home sick visits for telemedicine, too, so that our patients that are wheelchair bound in the wintertime can be seen in their home with one of our nurses going out in their home rather than coming all the way into the hospital. We answer all of our own phone calls on our patients as well. The patients get either one of the physicians or nurse practitioners in the program. We don't use a nurse triage line that would send the vast majority of our patients to the emergency room because they really are very complex. We know our patients; we know our families and we work with them to try to stay out of the hospital as much as possible, to be seen the next day in our clinic. If they do need to go to the hospital, we call in advance and let them know why the child is coming, what our concerns are for them, and a place to start rather than, again, starting from scratch.

Dr. Smith: Along with reducing hospital admissions, what are some of the goals of The Beacon Program?

Dr. Hoffman: We want to decrease hospital visits, both in number and in the length of the stay. Some

patients in the hospital will stay until they are off of oxygen, for example, or until they are tolerating all of their feedings. If we know that patient, that family, we can continue to do that as an out-patient. We will let the team know we're ready to take over and send them out. We don't want them to go to the emergency room unless they absolutely have to so have been working on that. We want to improve their overall satisfaction, too. The satisfaction with our program has been really phenomenal. Our families, I think, our some of our best cheerleaders because they like having someone who listens to them and looks at their child as a whole and not just as one organ or one body system and is willing to work with them and their desires for their child. We have decreased the emergency room visits for this patient population by 10% in the last year. When we looked at a June to June timeframe. We have also decreased our admissions by 14% which is really astronomical considering that these are the patients that are really using healthcare dollars to the highest degree. I think it speaks to our ability to know our patients and families, work with them and even do a lot of management at home that traditionally would have been something that you would have done in the in-patient setting.

Dr. Smith: Dr. Hoffman, what is your personal goal for this and where do you see something like The Beacon Program going? Is this something you'd like to see nationally? What's the vision for the program?

Dr. Hoffman: I think that we are creating a model that is one that could be replicated nationally. We are working with a lot of different children's hospitals across the country right now in terms of trying to find out what are the best ways to help these patients and their families. Our model is a little bit different than some of the other models across the country. There are some that do just consultative work, some that do just primary care. There aren't many that are crossing both into the in-patient and out-patient realm and additionally taking care of healthy siblings. That is something that we offer in our program to our families that is a bit unique. So, parents can have a one-stop shop for their whole family if they desire. Or, if they want to use the doctor across the street for their healthier children and then drive a little bit longer to see us, we are open to that as well. But, I think that it's a model that can exist in other areas of the United States. We think it's working for us and it's working for our families and we would like to see this type of a model exist elsewhere.

Dr. Smith: Dr. Hoffman, thanks for all that you are doing. The Beacon Program really does sound wonderful and I'm very happy with the success you're having with it. I want to thank you for coming on the show. You're listening to *Transformational Pediatrics* with Children's Mercy Kansas City. For more information you can go to ChildrensMercy.org. That's ChildrensMercy.org. I'm Dr. Michael Smith. Thanks for listening.