

September 5, 2018

The Honorable Greg Walden  
Chairman  
Committee on Energy and Commerce  
U.S. House of Representatives  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Frank Pallone, Jr.  
Ranking Member  
Committee on Energy and Commerce  
U.S. House of Representatives  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Michael Burgess  
Chairman  
Health Subcommittee  
Committee on Energy and Commerce  
U.S. House of Representatives  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Gene Green  
Ranking Member  
Health Subcommittee  
Committee on Energy and Commerce  
U.S. House of Representatives  
2125 Rayburn House Office Building  
Washington, DC 20515

Dear Chairman Walden, Ranking Member Pallone, Chairman Burgess and Ranking Member Green,

As the President of St. Joseph's Children's Hospital in Tampa, Florida, I am writing to express my strong support for the Advancing Care for Exceptional Kids Act of 2017, often referred to as the ACE Kids Act (H.R. 3325).

This legislation has the opportunity to make a significant, positive impact for millions of medically complex children and their families in the State of Florida and across our country, while also resulting in considerable savings for U.S. taxpayers. I am very pleased to have the opportunity to submit comments in support of its passage as the Health Subcommittee considers its merits.

The ACE Kids Act aims to improve how we deliver critical health care services to children who are among the most medically complex and vulnerable in our country. In doing so, it also has the potential to save the U.S. government billions of dollars over the course of 10 years. It is a win all around – improving care for our most complex children, enhancing the quality of life for these kids and their families, and ensuring more efficient, effective use of limited healthcare resources.

To do so, the legislation utilizes a 'health home' concept, facilitating coordination of care for medically complex children.

Our direct experience with the health home concept at St. Joseph's Children's Hospital of Tampa allows me the ability to share with you first-hand just how impactful this model is for our most complex children and the families who love them. Roughly 16 years ago, a visionary pediatric critical care doctor named Dr. Daniel Plasencia created the Chronic-Complex Clinic, which is located on the campus of St. Joseph's Children's Hospital of Tampa. The Clinic today serves as a health home to approximately 700 children with complicated medical problems and severe disabilities, while additionally providing support to the entire family.

Included among them is 5-year-old Lucia "Lucy" Ferlita, who is the only child living in the United States with a diagnosis of EMARDD, or early onset myopathy with areflexia, respiratory distress and dysphagia. Very little is known about this serious disease, which has left Lucy with low muscle tone and the need for a feeding tube to eat and a ventilator to breathe. Lucy requires nursing care 24 hours a day, seven days a week. The Chronic-Complex Clinic at St. Joseph's Children's Hospital of Tampa coordinates all aspects of her care. Lucy started kindergarten at her neighborhood elementary school just a few weeks ago in good health and good spirits.

Our Chronic-Complex Clinic at St. Joseph's Hospital of Tampa also serves as the medical home of Lakota Lockhart of Plant City, Florida. Now 9 years old, Lakota was born with congenital central hypoventilation syndrome, a central nervous system disorder which causes his breathing to stop every time he falls asleep. The condition is extremely rare, affecting less than 1,500 people throughout the world. Lakota spent the first 68 days of his life in the Neonatal Intensive Care Unit, where he underwent multiple surgeries to insert a feeding tube in his stomach and a breathing tube in his trachea. A team of pediatric specialists at the Chronic-Complex Clinic provides his care, including a pulmonologist, neurologist and gastroenterologist. Lakota is a frequent visitor at the Clinic, where his continued love for his favorite superhero, Batman, remains a primary topic of conversation with those rendering his care.

Finally, members may recall testimony delivered before this subcommittee in July 2016 by Tish West of Tampa, Florida, who is mother to Caroline West. Now 21 years old, Caroline has a rare neurological condition known as Alternating Hemiplegia of Childhood, which is only diagnosed in 800 people worldwide. As Caroline's mother described to this subcommittee, Caroline's condition impacts every aspect of her life. She has seizures, cannot eat by mouth, and is confined to a wheelchair. Caroline is developmentally delayed and has cerebral palsy. A team of nearly 30 different specialists is needed to care for Caroline to ensure her health and wellbeing.

Better than any words I am able to write, Tish's own description to the Health Subcommittee two years ago is able to best convey the life-changing impact of the health home concept offered by the ACE Kids Act: "We are 'normal' at our Clinic. We are not an outlier. Since coming to the Clinic, Caroline's health has improved and her hospitalizations have reduced tremendously. Our family feels welcome and embraced at the Clinic. All of the nurses and staff know Caroline and our family...our entire family has benefited from this Clinic."

In addition to my role as hospital president, I am also a caregiver – serving for many years as a pediatric and flight transport nurse. I feel passionately about doing all that we can to provide the best possible care for children and their families.

The ACE Kids Act offers a mechanism by which we as a community of health care stakeholders might vastly improve the quality of life for our country's medically complex children and those who love them. I strongly support this legislation and urge the Health Subcommittee to support its passage.

Thank you for your time, consideration and work to improve the health and wellbeing of our children.

Sincerely,

Kate Reed, RN  
President, St. Joseph's Children's Hospital  
Tampa, Florida

Enclosures

CC: Members of Energy and Commerce Committee



# Lucia Ferlita

**Age: 5**

**Hometown: Tampa, FL**

**Hospital: St. Joseph's Children's Hospital**

Lucia, aka Lucy, is a bright and social 5-year-old girl who has a natural love for learning and enjoys puzzles, her iPad and being with her mom, dad and little brother. She looks forward to going to her neighborhood elementary school five days a week with her private-duty nurse, where she will attend kindergarten next year.

Lucy is also the only person living in the United States with a diagnosis of EMARDD, or early onset myopathy with areflexia, respiratory distress and dysphagia. Very little is known about this serious disease that has left her with low muscle tone and the need for a feeding tube to eat and a ventilator to breathe. She requires nursing care 24 hours a day, seven days a week.



Lucy appeared healthy at birth but began showing signs of distress when, at 8 weeks old, she stopped eating. Before she was even 6 months old, Lucy had undergone four surgeries to place a feeding tube, get a stomach wrap (Fundo Plication), conduct a muscle biopsy and insert a tracheotomy.

The family searched for medical answers, struggled for resources to cover medical bills, and lived every day just hoping to keep their daughter alive. They truly knew what was at stake; Lucy's older brother, Vincent, was just 6 months old when he died from what doctors now know was the same disease.



Fortunately, Lucy has found a medical home in the Chronic-Complex Clinic at St. Joseph's Children's Hospital. As a nationally recognized medical home for children with multiple life-threatening conditions, the Clinic coordinates all aspects of Lucy's highly specialized care. Her mom, Lisa, credits the center for keeping her young daughter in good health and out of the emergency room.

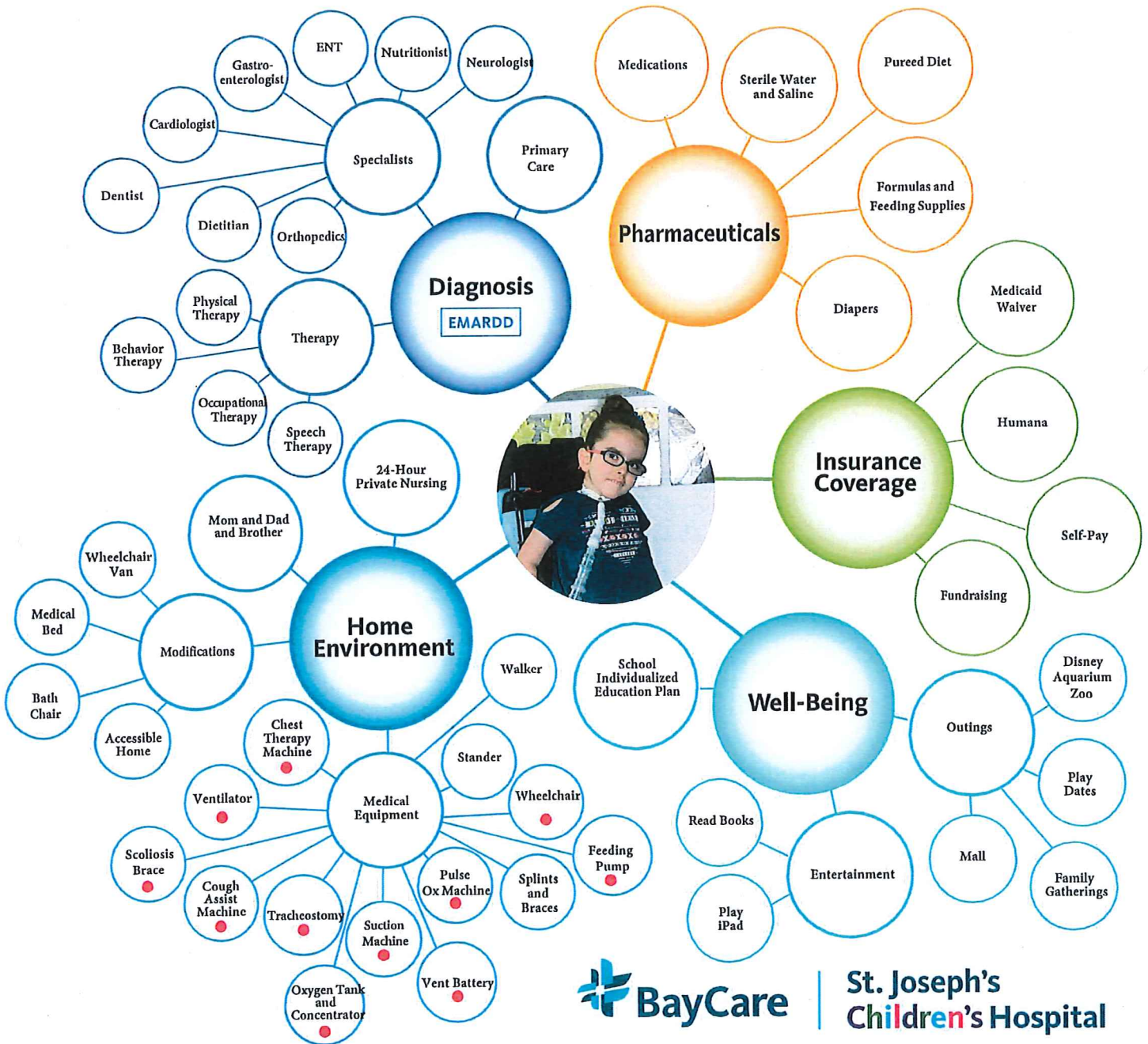
"The team at St. Joseph's Children's Hospital knows Lucy and her very particular, special needs," said Lisa. "Everything about Lucy's medical condition is complicated. Getting out of the house to go anywhere requires a tremendous amount of equipment and brings some risk to her delicate condition. But the progress Lucy has made since we found the Clinic is remarkable. I cannot imagine managing her care without it."



# Lucia's Story

A care map by Lucia's parents illustrates the complexity of integrating her health care needs into everyday life.

Lucia's parents mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of her health care into everyday life. Lucia is the only person in the U.S. diagnosed with early onset myopathy with areflexia, respiratory distress and dysphagia (EMARDD). ● Red dot = must go wherever Lucia goes





# Lakota Lockhart

**Age:** 9

**Hometown:** Plant City, FL

**Hospital:** St. Joseph's Children's Hospital

Lakota is an imaginative and energetic 9-year-old boy who loves to tell stories about his favorite superhero, Batman.

He was born with congenital central hypoventilation syndrome, a central nervous system disorder which causes his breathing to stop every time he falls asleep. The condition is extremely rare, affecting less than 1,500 people throughout the world.



Lakota spent the first 68 days of his life in St. Joseph's Children's Hospital's Neonatal Intensive Care Unit, where he underwent multiple surgeries to insert a feeding tube in his stomach and a breathing tube in his trachea.

He then transitioned to the hospital's Chronic-Complex Clinic, where he receives care from a team of pediatric specialists including a pulmonologist, neurologist and cardiologist. The Clinic serves as a medical home for patients like Lakota, and has been recognized nationally for its innovative work with medically complex children.

"St. Joseph's Children's Hospital has been instrumental in my son's survival," said Lakota's mother, Krystal Lockhart. "From the moment we received the devastating diagnosis six years ago, to the life-saving care Lakota continues to receive today, the hospital's team of specialized caregivers have been there for us every step of the way.



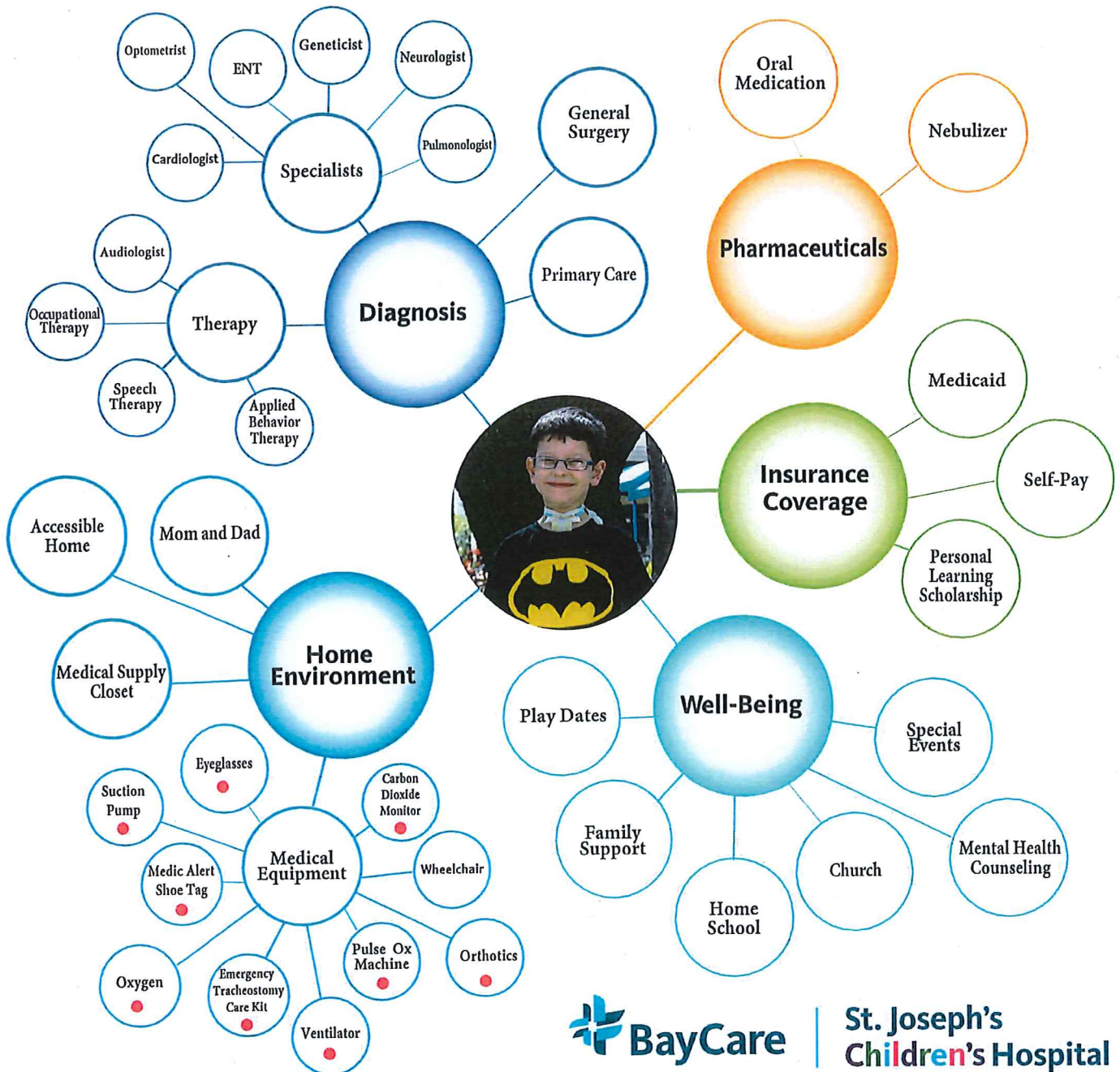
Lakota is typically covered by Medicaid and participates in Florida's Children's Medical Services Program, but is currently covered by commercial insurance. With a lifetime of specialized care and medical equipment in his future, this coverage is a critical lifeline to his family.



# Lakota's Story

A care map by Lakota Lockhart's parents illustrates the complexity of integrating his health care needs into everyday life.

Lakota's family mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of his health care into everyday life. ● Red dot = must go wherever Lakota goes





# Caroline West

**Name:** Caroline West

**Age:** 21

**Hometown:** Tampa, FL

**Hospital:** St. Joseph's Children's Hospital



She loves music, enjoys school and has even been to prom, but Caroline is definitely not a typical teenager. That's because a rare genetic condition has left her with severe physical and mental disabilities that require constant supervision and more than a dozen medical professionals directly involved in helping her manage the disease.



Caroline was born five weeks early, then suffered a seizure and stopped breathing in the first 12 hours of her life. The doctors did not diagnose her for several years because she has an extremely rare neurological disorder, Alternating Hemiplegia of Childhood (AHC), which is only diagnosed in 800 people worldwide. Prior to her diagnosis, Caroline was tested and evaluated extensively at Johns Hopkins, Columbia Presbyterian and Boston Children's Hospitals.

Besides AHC, Caroline also has cerebral palsy and a seizure disorder. As a result, she cannot walk, has speech and motor delay, and is developmentally delayed. She attends school part-time in a specialized classroom and receives speech, physical, and occupational therapy weekly. She has a GI tube for nutrition, has had her spine fused and has extensive specialized equipment at home to meet her daily living needs.



Caroline's medical home is the Chronic-Complex Clinic at St. Joseph's Children's Hospital. The clinic coordinates Caroline's health care needs, which include daily nursing care, physical, speech and occupational therapy, medical supplies, durable medical equipment, medical care and communication between all of her specialists.

See Caroline's story and learn more about the clinic at

<https://www.youtube.com/watch?v=nsVxL115jTk>.

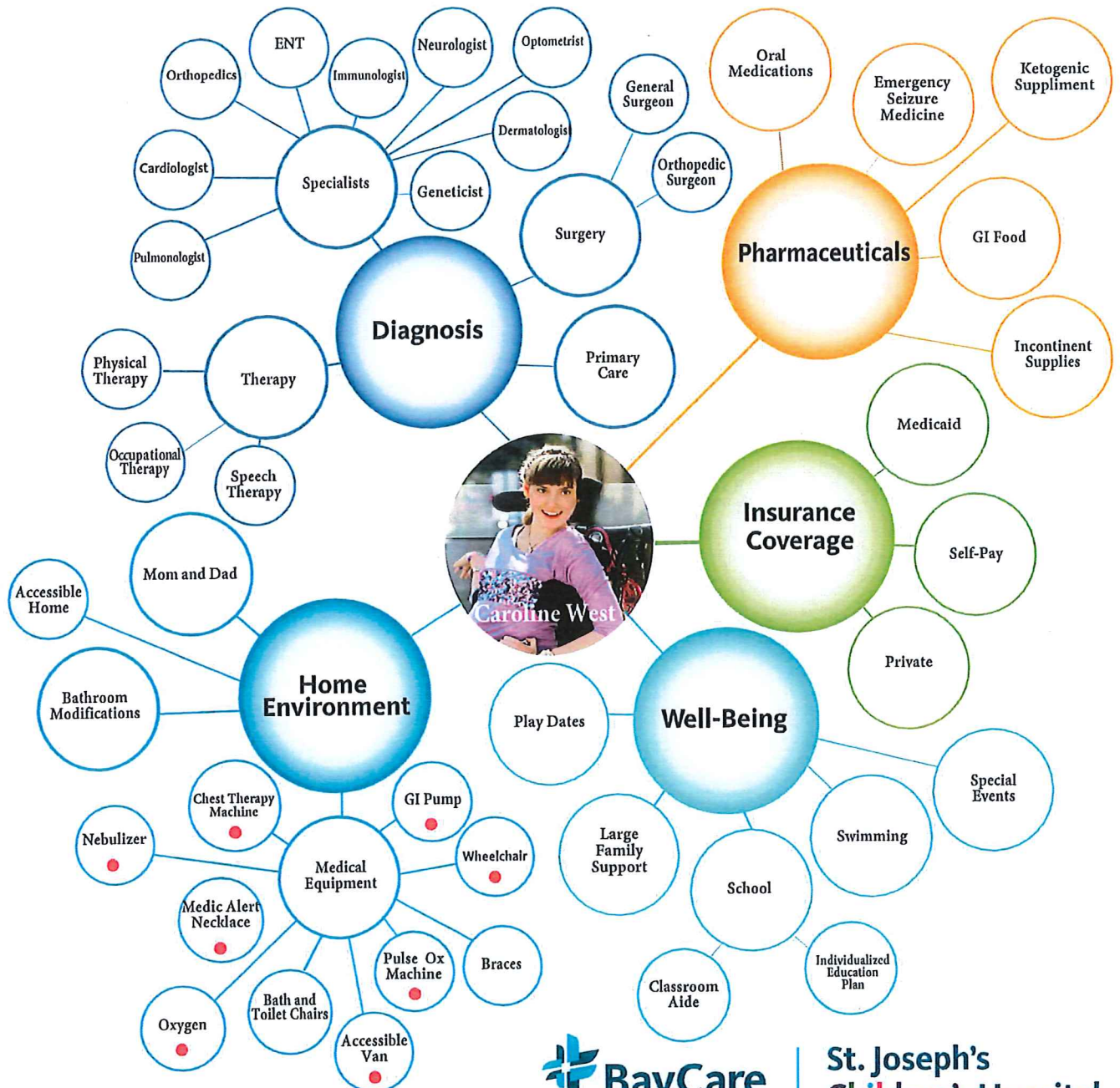


# Caroline's Story

A care map by Caroline's parents illustrates the complexity of integrating her health care needs into everyday life.

Caroline's family mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of her health care into everyday life.

• Red dot = must go wherever Caroline goes





# Jaden Vidal Velasquez

**Age: 10**

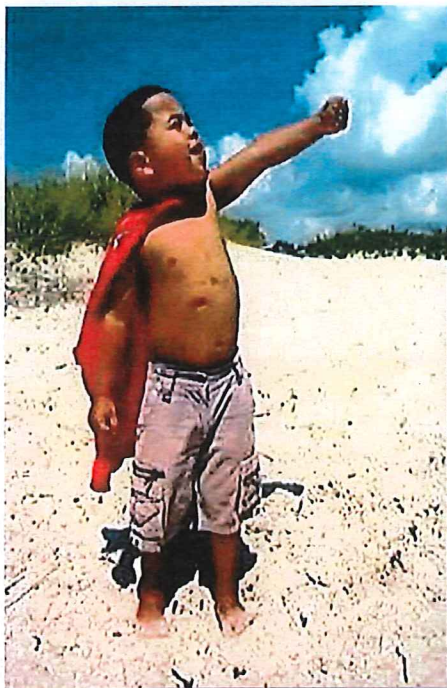
**Hometown: Tampa, FL**

**Hospital: St. Joseph's Children's Hospital, Tampa, FL**

Jaden is a sweet, loving and happy 10-year old who loves swimming, Tae Kwon Do, soccer and going to school. Born with hypoplastic left heart syndrome, a congenital heart defect in which the left side of the heart is severely underdeveloped. At just 4 days old, Jaden underwent open-heart surgery. Since then, he has undergone two additional open-heart surgeries, several catheterizations, the insertion of a gastric feeding tube, and months of physical rehabilitation.



St. Joseph's Children's Hospital has been instrumental in Jaden's diagnosis, treatment and continuous care. His family is extremely grateful to receive all of his specialized care in one facility, and by compassionate caregivers specifically trained to treat Jaden's complex condition.



The Chronic-Complex Clinic at St. Joseph's Children's Hospital is Jaden's medical home. As a nationally recognized medical home for children with multiple life-threatening conditions, the clinic coordinates all of Jaden's pediatric specialists and care providers.

If it weren't for the scars on his chest, you might never know Jaden was born with a heart defect. "Yes, he was born with half a heart, but it's a strong half a heart and it belongs to an amazing and perfect child," says Jaden's mother, Belkis.

For the first three years of Jaden's life, Medicaid covered nearly all of Jaden's care, including his heart surgeries, hospitalizations, visits to his pediatric specialists, and medical equipment.

Today, Jaden is a national ambassador for Speak Now for Kids, a patient advocacy organization. His family believes this honor gives them the opportunity to speak out on behalf of other children with complex needs as well as the importance of obtaining affordable, comprehensive health care coverage. Jaden and his family understand this all too well.

Jaden is now covered by the Children's Health Insurance Program (CHIP). With a potential heart surgery in the future and a lifetime of medications, this coverage is a critical lifeline to Jaden's family. To learn more about the Chronic-Complex Clinic please visit: [www.sjbhealth.org/Chronic-Complex-Clinic](http://www.sjbhealth.org/Chronic-Complex-Clinic).