

# Full PEDS Ahead

An Initiative for Mary Free Bed kids



## Hello Friends,

Your generosity has enabled us to improve the lives of an additional 1,177 kids over the past year who otherwise could not have received rehabilitative care.

Insurance reimbursement for chronic pain, autism, and early movement conditions, including cerebral palsy, continues to be inadequate or nonexistent for kiddos facing these challenges.

Because of you, these kids have had the chance to maximize their potential. You have funded treatment spaces, specialized therapies, and access to essential care — significantly easing the financial burden on families who are already distressed about their child's condition and care coordination.

Since its inception, the General Movement Assessment (GMA) has been a cornerstone of our Early Development Program. It allows clinicians to diagnose cerebral palsy within the first few weeks or months of a baby's life and begin therapy immediately. We have long dreamed of harnessing the power of advanced technology to help diagnose cerebral palsy and other conditions characterized by atypical movement patterns. This dream is now close to becoming a reality. A beta version of our mobile app has been developed, bringing us closer to making the GMA more widely available, which will benefit more infants and children in West Michigan, throughout our state, and around the world.

Your unwavering commitment and generosity have fueled the growth and success of Full Peds Ahead. Together, we're helping our youngest patients build brighter futures.

Kent Riddle CEO
Mary Free Bed Rehabilitation Hospital

# **Autism Spectrum Disorder**

Autism Spectrum Disorder (ASD) is estimated to affect one in 36 children in the U.S., according to the Centers for Disease Control and Prevention (CDC). New data is also helping us better understand how the pandemic caused a delay in early identification of autism in young children — impacting current and future needs as these learners are getting older.

Boys are about four times more likely to be diagnosed than girls, and the condition occurs in all racial, ethnic and socioeconomic groups. There is still much work to be done in improving access to screening, awareness, and access to services among historically underserved groups.

Research shows that increased awareness, early diagnosis, and timely intervention can help children access individualized support and services sooner. Mary Free Bed specializes in diagnostic and intervention therapies for children with ASD, including Applied Behavior Analysis (ABA) therapy. We offer this therapy in Grand Rapids and Bay City through our joint venture with Covenant HealthCare.



#### **TREATMENT**

Autism looks different for every child. Kids with ASD often have different ways of learning, moving, or concentrating. It presents on a spectrum, meaning each learner requires individualized treatment plans with goals specific to their unique skills and challenges.

There are several therapies that can be incredibly beneficial. Speech therapy can enhance communication skills, occupational therapy can teach essential daily activities, and physical therapy can improve movement and balance.

At the heart of our program is Applied Behavior Analysis (ABA) therapy, which is comprised of evidence-based strategies that have consistently proven to be effective and impactful. Through ABA, children learn to understand and modify behaviors. Therapists work with kids to focus on fostering positive, helpful actions while reducing those that hinder learning and development. The frequency and duration of therapy are customized for each patient, often ranging from 20 to 40 hours per week over several years, ensuring the best outcomes for their development.





#### **ACCOMPLISHMENTS**

#### **Collaborative Care**

We've welcomed an additional occupational therapist and a psychologist in Grand Rapids. The psychologist plays a crucial role in diagnosing autism and ADHD, providing families with the insights and support they need.

Our program continues to thrive through ongoing collaboration with pediatric occupational, speech, and physical therapists within Mary Free Bed, as well as with external organizations, educators, doctors, dentists and other professionals. This integrated approach ensures comprehensive care tailored to each child's unique needs.

#### **Enhanced Tools**

We enhanced our therapy spaces with new equipment designed to encourage sensory play, facilitate socialization with peers, and boost skill acquisition. We've also invested in advanced technology to improve data collection, ensuring we can track and optimize each child's progress effectively.

## Family Support & Community Engagement

Having autism affects not only the child but the entire family. We understand the importance of providing resources and support for the whole family unit. This past year, we hosted two Parent's Night Out events, created an ABA policies and procedures handbook for families, and organized an autism workshop for families and the community. Additionally, we collaborate closely with families to initiate the school transition process early during treatment, ensuring a smooth and successful transition.

#### GOALS

Each learner will master, or make significant progress toward, 75% of their personal goals during their treatment period. We aim for all learners to meet at least 50% of their personal goals by their six-month assessment. Personal goals for our learners include:

- Establishing and improving communication skills
- Developing appropriate social/relationship skills
- Building adaptive/self-help skills
- Establishing alternatives to challenging or dangerous behavior

#### CHILDREN SERVED'-





36,000 therapy hours

\*ABA program

#### **FUTURE PLANS**

## **Expanding Our Reach**

The goals of the Centers for Autism in Grand Rapids and Bay City are uniquely tailored to the age ranges each center serves. The Grand Rapids program supports children and young adults aged 2 to 20 years old, while the Mary Free Bed at Covenant HealthCare program focuses on children aged 2 to 8 years old. To ensure consistent and effective care, both programs are working on creating a standardized assessment to set and measure individual goals.

## **Meeting the Growing Demand**

In response to the high demand for autism treatment services, we are excited to announce expansions at both centers. Mary Free Bed at Covenant Center for Autism is opening a second location in the Midland area, complementing the existing facility in Bay City. Meanwhile, the Center for Autism in Grand Rapids is expanding within its current location, adding an indoor play structure, sensory activities and additional treatment rooms.

## **Growing Our Team**

As these new treatment spaces open, we plan to hire additional therapists to meet the needs of our growing community. This expansion will allow us to provide more children with the high-quality, personalized care they deserve.



## Cerebral Palsy and Early Development

Cerebral palsy (CP) is the most common motor disability in children. It's caused by an injury to a developing brain or atypical brain development — usually before, during or soon after birth. Kids with cerebral palsy may have differences in movement, posture and balance. It can also affect vision, hearing, speech and cognition.

It's a lifelong condition; there's not a cure, but research shows early therapeutic intervention can make a significant difference in a baby's healthy development.

CP is typically diagnosed after age 2, but research shows an earlier diagnosis and intervention helps to maximize the child's potential. In the Mary Free Bed Kids Early Development Program, our specialists evaluate infants for potential CP and other disabilities using the General Movement Assessment (GMA).

#### EARLY DIAGNOSIS IN THE PROGRAM

Our specially-trained team members are experts in the treatment of neurologic, neuromuscular and developmental disabilities in kids. GMA is a non-invasive, evidence-based assessment used to identify atypical movement patterns, allowing for immediate intervention in our Early Development Program. We care for babies from birth to the age of three. And we can help any child, not just those born prematurely or those who had a traumatic birth.





#### GOALS

- 100% of patients up to 12 weeks of age evaluated in the Early Development Program will receive an individualized treatment plan based on a General Movement Assessment (GMA)
- · All patients receiving ongoing therapy services for Cerebral Palsy will complete a Patient Specific Functional Scale (PSFS) and identify the top three areas of function to address during treatment
- 80% of patients will achieve a Minimal Clinically Important Difference (MCID) increase of at least two points. The MCID scale measures improvements that are noticeable and meaningful to the child and family

#### CHILDREN SERVED





#### **ACCOMPLISHMENTS**

#### **Growing our Team**

Our CP therapy team grew to accommodate more patients and therapy hours. We added two pediatric occupational therapists and two speech therapists to the team.

#### **Raising the Bar for Early Diagnosis**

The General Movement Assessment remains an integral part of identifying movement patterns to determine if early therapy services are needed. Nearly every child seen in the Early Development Program under the age of 16 weeks undergoes a GMA.

#### **Collaborative Care**

We increased collaboration with Trinity Health Grand Rapids NICU to evaluate swallowing function on newborns prior to their departure from the hospital. We continued collaboration with Corewell Health Helen DeVos Children's Hospital and the Advanced Management of Pediatric Spasticity Program for children with cerebral palsy to coordinate and prioritize care.

#### **FUTURE PLANS** •

We're excited to continue growing and expanding our program, providing high-quality care from birth onward. While we've focused a lot on our youngest patients at risk for developing cerebral palsy in recent years, we're now eager to support our older pediatric patients as they prepare to transition to adulthood.



## Chronic Pain

Chronic pain is a complex condition that can last for months or even years. It's different than acute pain which typically resolves on its own. This persistent pain can significantly impact a child's physical and emotional well-being. It can prevent them from participating in activities they enjoy and may lead to social isolation, depression and anxiety.

Our Chronic Pain Program aims to help children and adolescents manage their pain and regain their quality of life. Our team of specialists is dedicated to helping patients live pain-free lives through a variety of innovative treatments.

At Mary Free Bed Rehabilitation, children and teens learn to reduce and manage their pain, allowing for increased function and quality of life. Mary Free Bed and Corewell Health Helen DeVos Children's Hospital are the only two health care organizations in West Michigan that offer treatment for pediatric chronic pain. Families often travel great distances to access this specialized care. Thanks to funding for this program, children who otherwise would have faced barriers to treatment can receive the care they need.

#### TREATMENT

Interdisciplinary pain rehabilitation specialists at Mary Free Bed understand the complexities of chronic pain. They work with children and their families to create a customized treatment plan that addresses their individual needs. This can include physical therapy, occupational therapy and psychology. Through treatment, we help to:

- Lessen the interference of pain in daily activities
- Increase physical functioning
- Reduce anxiety regarding pain
- · Increase participation in sports, recreational and social activities
- Develop adaptive approaches to dealing with pain

#### CHILDREN SERVED



100 treated



**9** 1,191 visits





## TAKING THE MOUND AGAIN

Last year, 16-year-old Korrie Schuurman, of Byron Center, Michigan, thought she'd never play softball again. After battling long-haul COVID, Korrie was diagnosed with postural orthostatic tachycardia syndrome (POTS). Last summer, she injured her ACL during softball practice, adding to her stress and worsening her condition.

Korrie struggled with extreme fatigue, breathlessness, and instability, which led her to transition to homeschooling. A trip to the ER and care at Corewell Health Helen DeVos Children's Hospital revealed another diagnosis: functional neurological disorder (FND).

In November 2023, Korrie's arrival at Mary Free Bed Kids brought hope. An interdisciplinary team of doctors and therapists focused on helping her regain control of her body through intensive, physical, occupational and psychological therapies.

By March, Korrie had made extraordinary progress. She returned to school and is now back to the joys of her teenage life. This spring, she achieved her #1 goal: stepping back onto the mound as a pitcher for her high school varsity softball team.

Korrie hopes to one day return to Mary Free Bed as an occupational therapist. She and her mom shared their very special perspectives on life, perseverance, and the healing journey. Scan the QR code to learn more.



#### **MEET KORRIE**

maryfreebed.com/stories/meetkorrie



#### GOALS

- 80% of patients will achieve an increase of 2 points or greater (MCID\* is 2) on the Patient Specific Functional Scare (PSFS) as an indicator of improved function that is meaningful to the patient
- Patients will average a minimum of a 5-point reduction on the Functional Disability Index (FDI)
- Patients will average a minimum of a 3-point reduction on the Patient-Reported Outcomes Measurement Information System (PROMIS) Depression and/or Anxiety Measures

#### **ACCOMPLISHMENTS**

#### **Growing our Team**

We expanded our team of Chronic Pain specialists, which is led by Dr. Douglas Henry. Last year, we welcomed a new pediatric pain psychologist to Mary Free Bed Kids. Dr. Kyleigh Skedgell joined us in November 2023 and sees kids in inpatient and outpatient settings at the Grand Rapids campus. We also expanded programming to include the disciplines of physiatry, psychology, physical therapy and occupational therapy.

#### **Caring for More Patients**

We've improved the coordination of therapy schedules to accommodate multiple appointments in a single day. This change has been especially beneficial for those who need to travel over an hour to get to Mary Free Bed.

#### **FUTURE PLANS**

We will continue to collaborate with Corewell Health Helen DeVos Children's Hospital to expand the peds pain program when Joan Secchia Children's Rehabilitation Hospital opens. We would like to expand services to include the discipline of social work for additional parental support as well as recreational, art and music therapies to help with children's coping skills. These disciplines will allow us to provide more comprehensive care to patients and their families.

The Steve & Amy Van Andel Foundation provided a significant gift to further this work.



Established by The Steve & Amy Van Andel Foundation

Mary Free Bed — along with its generous supporters — subsidizes the *Full Peds Ahead* effort at nearly \$1 million annually.

Thank you, we're grateful for your support.



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