FALL/WINTER 2021

WECARE CLINIC MESSENGER

WeCare Clinic
Medical Care for Special Needs

WeCare Clinic – Medical Care for Special Needs, 775 Pembroke Fairview Road, Pembroke, KY 42666
Phone: 270-962-7383 Fax: 270-962-7385

A Year of Growth

From providing complex medical care to working in administrative capacities behind the scenes, our staff have had the opportunity to help many patients and families. In the first year of operation, we already have 215 active patients receiving specialized care at WeCare. We have been blessed beyond measure in our first year of operation.

The work of assisting our families goes well beyond a visit at the clinic. Prior to each appointment with a family and after determining diagnoses our medical staff spend time researching and studying genetic conditions and possible treatment options for our patients. We are also involved in linking families to resources outside of WeCare Clinic such as a children's hospital or cost-saving measures for medicine.

Most recently we have been providing care for patients with Down's Syndrome, Hyperglycinuria, Wolf Hirschorrn Syndrome, Polymyalgia rheumatica, KPTN related Macrocephaly and Epilepsy, Statin-Induced Myopathy, Galactosemia, Chromosome 14 and 16 abnormality, Chromosome 1 abnormality, Ataxia Type 2, and several patients are awaiting a diagnosis.

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A Year of Growth (cont.)

Our compassionate and knowledgeable staff stand ready to provide care for your family Monday through Friday. ***If you have a diagnosed genetic condition or suspect a genetic condition and you are interested in becoming a patient of WeCare Clinic, call 270-962-7383 or write us to request new patient forms.***

Early Diagnosis Gives Newborns Better Outcomes

Fall has arrived here in Kentucky—bringing pumpkins, beautiful mums, and a surge in newborn babies born with rare, genetic conditions.

Some of these babies had a newborn screening that was positive and were taken first to a hospital where they received life saving measures and stabilization before their care was then transferred to our clinic for management.

Some of the other babies that we are caring for had a known risk before they were born because of the parents' known disease carrier status. These babies did not have to go to the hospital. Our clinic worked together with the midwife to send off cord blood right after birth. We were able to get a diagnosis within 24 hours and to work proactively with our collaborating medical professionals to bring forth the best outcome for the baby (most importantly) without the added cost and stress of a hospital stay.

The newborn screening is an important tool that detects rare, genetic disorders. It is sent to the state by the midwife or medical staff. Each state tests for different disorders. Kentucky tests for 53 genetic disorders (Commonwealth of Kentucky Cabinet for Health and Family Services, 2017). The turnaround time for this test currently is 7-10 days.

The carrier testing that is performed at our clinic is sent to the Clinic for Special Children (CSC) and tests for around 1,300 genetic variants that are disease causing. This test is called the Plain Insight Panel (CSC, 2021). It is recommended for anyone 18 and above.

Both of these tools are important to provide early diagnosis, a healthy outcome, decreased disability, and decreased costs to the family and community. We are currently looking for communities interested in hosting an outreach clinic for carrier testing. Please call our clinic at 270-962-7383 if your community is interested.

- Jolene Schmucker, APRN

What Are We Diagnosing at WeCare Clinic? A Spotlight on Galactosemia

An Amish couple's first child was delivered by the midwife with no complications and starts to breast feed. The first couple of days the child seems well, but then Grandma notices that the baby just isn't eating well, was jaundiced, and somewhat floppy. Grandma's intuition told her something was not right with this baby. Shortly thereafter they receive a call about the newborn screen and are informed that the baby has galactosemia and needs evaluated at the hospital. The parents followed that advice.

The parents took the baby to the emergency room and the baby was found to be very ill with dehydration, an elevated white cell count, low platelets, elevated liver enzymes, and developed problems clotting blood. The baby was admitted and treated for potential bacterial infection (which babies with galactosemia are prone), started on IV's for dehydration and correction of electrolytes (sodium, potassium, etc.), and given formula that contained no lactose. This child ended up with an extensive inpatient stay. Tests were performed while the child was in the hospital and was subsequently diagnosed with classic galactosemia.

What is Galactosemia?
Galactosemia is a disorder in which the baby has an inability to convert galactose (a sugar in milk, including human mother's milk) to glucose (a sugar the human body needs to function). The infant will appear normal at birth, but within several days loses its appetite and then starts to vomit, jaundice occurs, the liver becomes inflamed, and abnormal amino acids and protein appear in the urine, growth failure occurs, and ultimately death. Some children who do survive undiagnosed, have poor growth, mental delay, severe cataracts in infancy or childhood, severe infections, liver failure, kidney failure, and brain damage. Treatment of galactosemia is the immediate removal of lactose from the diet. Even with treatment, later complications can occur, such as speech and learning difficulties, behavioral problems, ovarian impairment leading to problems with reproduction.

What causes Galactosemia?
Galactosemia is caused by mutations in the GALT gene resulting in a deficiency of the GALT enzyme (galactose-1-phosphate uridylyl transferase) which leads to an inability to convert galactose in milk to glucose. This enzyme deficiency leads to the toxic accumulation of galactose-1-phosphate (a derivative of galactose), and galactitol (an alcohol derivative of galactose). Galactitol accumulates in the lens of the eye where it causes lens swelling, protein precipitation, and subsequently cataracts. Accumulation of galactose-1-phosphate is thought to cause the other signs and symptoms of disease.

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What Are We Diagnosing at WeCare Clinic? A Spotlight on Galactosemia (cont.)

How is it inherited?
Galactosemia is an autosomal recessive genetic disorder. Each parent must contribute one abnormal gene to the child for the disease to manifest in the infant. If the child receives only one abnormal gene from one parent and a normal gene from the other, the child will be carrier for galactosemia. If that child marries a partner who is a carrier for galactosemia, then they will have a 25 percent risk of having a baby with galactosemia.

Prevention of Complications
What can we do to prevent complications and hospitalizations from unexpected cases of galactosemia? One preventative strategy is newborn screening. Another step that families can take is if you know that galactosemia runs in your family, then you and your spouse can undergo PIP screening (Plain Insight Panel) which can determine if you are a carrier of galactosemia or other genetic disorders that can be passed on to your newborn. If you are carriers for galactosemia, you have a 25 percent chance of having an infant with galactosemia. If the WeCare Clinic is aware that an unborn child is at risk for galactosemia, when that child is born, we can order rapid testing through the Clinic for Special Children for the gene specific for galactosemia and if positive start the appropriate diet and prevent the complications that would be brought on with continued feeding of lactose. A hospitalization can be avoided.

Treatment
Treatment is lifelong avoidance of lactose containing products. If the child has developmental disabilities, then appropriate therapies will need to be provided.

If your family has a history of galactosemia and you would like to discuss PIP testing, we would be happy to assist.

This review only covers Classic Galactosemia. For more information you can refer to the National Organization for Rare Diseases.

- Dr. Gregory D. Mock
Medical Director

WeCare Clinic
Medical Care for Special Needs

WECARE STAFF:

- Matthew L. Hunt, EdD
  Interim Executive Director
- Gregory D. Mock, MD
  Medical Director
- Jolene Schmucker, APRN
  Nurse Practitioner
- Marlene Schmucker, RN, BSN
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WECARE BOARD OF DIRECTORS:

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Visit our Website

To learn more about WeCare Clinic, our services, upcoming events, and latest news, please visit:

www.wecareforspecialneeds.org

Multiple Ways to Support WeCare Clinic

If you would like host a fundraiser auction, fish fry, or bake sale in your community, please call 270-962-7383 or 270-202-6603.

If you are a customer of United Southern Bank, you can set up monthly donation transfers to the clinic.

You can donate electronically one time or monthly on our website at www.wecareforspecialneeds.org

If you shop at Kroger, you can help support WeCare Clinic. The Kroger Community Rewards Program will donate a proceed of each purchase you make to the clinic. Simply visit customer service at Kroger and have them add WeCare Clinic to your Kroger card by searching for We Care Clinic - Medical Care for Special Needs either by name or RJ996I.

If you shop on Amazon, you can support WeCare Clinic. The AmazonSmile Reward Program will donate a proceed of each purchase you make to the clinic. Simply visit AmazonSmile to link your account to WeCare Clinic.

The Role of Donations in Reducing Medical Costs

WeCare Clinic is organized on a non-profit basis to provide a diagnostic and out-patient medical care facility for children and adults with genetic disease in the Amish, Mennonite, and English communities of Kentucky and surrounding states.

Families are already seeing improved outcomes and greatly reduced medical costs associated with the care they are receiving at WeCare Clinic. Hundreds of thousands of dollars have already been saved this calendar year due to early diagnoses of rare, genetic conditions and decreased hospitalizations of our patients. Our medical staff have been able to keep several patients out of the hospital with care at the clinic and care at home. According to physicians and multiple board of directors at the other genetic clinics, WeCare must maintain a focus of specialized, genetic care. There are multiple quick-care, primary care offices throughout Kentucky, but there are no genetic clinics similar to WeCare Clinic that care for special children and adults. The board remains committed to providing specialized care for children and adults with genetic disorders.

While there are close connections between WeCare Clinic and the other special needs clinics, they are separate nonprofit corporate entities, engaged in independent medical practices, and each supported by its own funding sources. WeCare Clinic follows the financial model of the other special needs clinics. Fees from medical services cover approximately 20% of the operating expenses and approximately 80% of the clinic's operating expenses are covered by donations, contributions from fundraising auctions and events, and grants. Genetic disease is an ongoing, lifelong foe; the commitment of donors to support and sustain a clinic for special children and adults is long term as well. The donations and fundraising initiatives allows WeCare Clinic to keep the price for services low and well below the cost to provide the specialized services.

The 3-6-5 Challenge

We appreciate the support of our individual and business donors, funds provided through community collections, and funds donated at our fundraising auction. **We will be kicking off a new fundraising initiative in 2022 called the 3-6-5 Challenge in which we will be seeking 365 day sponsors to pay for a day or days of operation.** Day sponsors can pay the full amount at one time or over twelve months of the calendar year. The annual budget for WeCare Clinic is $650,000, so that means it costs approximately $1,780.82 per day to operate the clinic. In addition to our goal of establishing fundraising auctions across the state, the option of the 3-6-5 Challenge will allow individuals, businesses, and communities to select a special day of the year to sponsor operations at the clinic. If you have any questions about stepping up to the 3-6-5 Challenge, please call 270-202-6603.

Upcoming Events:

Family Genetics Disease Day
Date: September 2022
Time: To Be Determined
Location: WeCare Clinic, 775 Pembroke Fairview Road, Pembroke, KY 42266

WeCare Clinic Fundraiser Auction
Date: October 2022
Time: To Be Determined
Location: Bluegrass Sales Stables, 205 Trenton Tress Shop Road, Trenton, KY 42286

Contact Us

If you have any questions about WeCare Clinic, please call 270-962-7383 or 270-202-6603. You can also write us at 775 Pembroke Fairview Road, Pembroke, KY 42266 or fax us at 270-962-7385.

The mission statement for WeCare Clinic is to improve the quality of life for families with genetic disorders through medical care, education, and research.

Please consider donating to WeCare Clinic as we strive to improve the quality of life for families with genetic conditions through medical care, education, and research. We are grateful for the support we have received this year. Approximately 80% of the clinic's annual operating expenses will be covered by donations, contributions, and grants. The commitment of donors to support and sustain a clinic for special children and adults is a long term commitment. Thank you for your support.

Thank you for making a donation to WeCare Clinic.

Make your check payable to: WeCare Clinic

Mail to: WeCare Clinic, 775 Pembroke Fairview Road, Pembroke, KY 42266

Donation Made By:_____

Address: _____

City: _____ State: _____ Zip Code: _____

Date: _____ Check # _____ Amount: _____

If you do not wish to send donations directly to WeCare Clinic, anonymous contributions may be made through the Anabaptist Foundation. Make your check payable to Anabaptist Foundation with WeCare Clinic Fund on the memo line.
Mail to: Anabaptist Foundation, 55 Whisper Creek Drive, Lewisburg, PA 17837.

☐ Check here if you wish to receive a tax-deductible receipt at the end of the year.

☐ Check here if this is a 3-6-5 Challenge sponsorship. _____ Paid in full _____ Paid monthly

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