

SPRING 2023

WECARE CLINIC MESSENGER



WeCare Clinic – Medical Care for Special Needs, 775 Pembroke Fairview Road, Pembroke, KY 42266
Phone: 270-962-7383 Fax: 270-962-7385 www.wecareforspecialneeds.org

Outreach Clinics Across Kentucky

WeCare Clinic staff traveled across the state to conduct outreach clinics to meet the needs of patients with rare genetic conditions.



We want to thank our host families in Cerulean, Elkhorn, Flemingsburg, Munfordville, and Smiths Grove for opening up their homes, shops, and schools to allow our staff to provide care for families living in the area.

At the outreach clinics, our staff provided medical care, genetic counseling, dietary education, and blood draws for genetic testing through the use of the Plain Insight Panel (PIP).



Outreach clinics also provide an opportunity for the medical staff at We Care Clinic to collaborate with staff from the other genetic clinics. Most recently, Karlla W. Brigatti, MS, CGC, from the Clinic for Special Children visited Kentucky to meet with patients.



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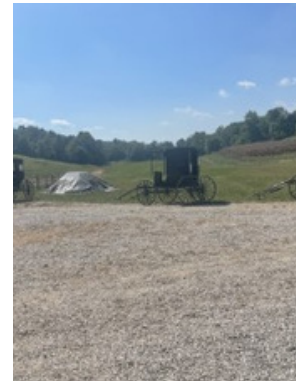
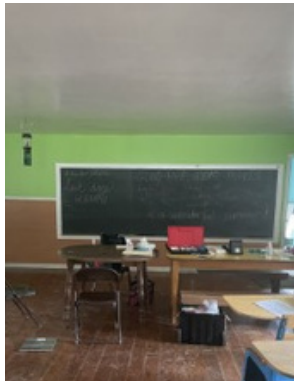
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Outreach Clinics Across Kentucky (cont.)

While outreach clinics are a great avenue to provide limited services, more services can be provided in the facility at WeCare Clinic. At the clinic we are not only able to do a variety of genetic testing to help diagnose, but we are also able to manage the care of patients with genetic disorders or special needs as a family-centered medical home. We are blessed to work locally with a lab that provides our patients with special needs a discounted price on labs that help reduce costs that these families must endure. If you are interested in becoming a patient of WeCare Clinic, call 270-962-7383 to schedule an appointment.

**By: Renee Spivey, RN and
Matthew L. Hunt, Ed.D.**



WeCare Clinic Welcomes New Staff

Tammy Sisk
Office Assistant



Tammy received her Certified Nurse Aide in November 2013 and Associate of Art from Hopkinsville Community College in May of 2017. Tammy started her medical career in 1986 at Jennie Stuart Medical Center, where she held many jobs from Unit Secretary, Radiology Scheduler, Education Coordinator and Human Resource Recruiter.

Lesley Moshier, RN
Registered Nurse



Lesley is a Hopkinsville native. She completed her Associate of Applied Science in nursing in 2016. Her background includes psychiatric, hospice, and long-term care nursing. In her free time Lesley enjoys watching documentaries, spending time with her family, and traveling.

A Rare Diagnosis - Aldosterone Synthase Deficiency (ASD)

In July of 2022 5-month-old Jacob Lengacher and his parents came to our clinic in hope of answers. He had already been hospitalized at a nearby children's hospital and was still struggling at home with symptoms of feeding difficulties, problems with weight gain, dehydration, and nausea/vomiting. Jacob's mother expressed her frustration of being unable to get answers or help for her baby boy.

While here at the clinic, Jacob was evaluated by our team and a thorough workup was performed including routine labs and genetic testing. He was admitted again to the hospital because of dehydration and low sodium. However, this was a temporary fix and when genetic results came back it showed that Jacob has a rare diagnosis of Aldosterone Synthase Deficiency (ASD) also known as Corticosterone Methyloxidase Deficiency.

ASD occurs when there are misspellings in the DNA instructions on the CYP11B2 gene. It is inherited when parents each have a mutation on this gene that are passed down to the child. This condition causes an imbalance in the sodium and potassium in the blood stream because the kidneys are releasing too much sodium through the urine. There is deficiency in a hormone called aldosterone which is in charge of making sure there is a balance of sodium and fluid within the body. Symptoms include nausea, vomiting, failure to thrive, muscle weakness, and dehydration. Sometimes it can even cause seizures, coma, and death.

Treatment for this condition utilizes a medication called Florinef which is a corticosteroid. This medication helps to replace the lack of aldosterone in the body and helps to create a balance with sodium and fluid. Sometimes children also need sodium replacement. Affected children usually outgrow this condition after several years and they no longer need medication or salt replacement.

Jacob continues to follow-up with our clinic through our outreach clinic in Flemingsburg, Ky. We collaborate with his endocrinologist and pediatrician to make sure that Jacob continues to stay healthy and grow.



By: Jolene Schmucker, APRN



Glutaric Acidemia Type 1 (GA-1)

Glutaric Acidemia Type 1 (also known as GA-1) is an inborn error of metabolism (IEM) of lysine, hydroxylysine and tryptophan. It is a very common IEM in the Plain communities. Patients with GA-1 are at very high risk for neurologic injury, particularly during the first few years of life. This neurologic injury is often preceded by illness or catabolic stress such as infection, but not always. The likelihood of injury is highest in untreated individuals, 80-90%, and therefore is part of the newborn screen. Close monitoring of diet and labs is essential to preventing injury.



By: Erin E. Teague MS, RD/N, LD

Lysine and tryptophan are amino acids (the building blocks of proteins) primarily found in animal products and whole grains. The goal of treatment is to limit intake of these amino acids and utilize medical formula to meet calorie, protein and micronutrient needs in order to promote appropriate growth and development. Medical formula used for GA-1 is free of lysine and tryptophan. The formulas may also supplement the amino acid arginine, which competes with lysine for absorption in the brain. Infants are treated with a combination of breastmilk or infant formula + medical formula. When solid foods are started, families need to work very closely with a Registered Dietitian (RD), to limit high lysine foods and provide enough calories. Special low protein foods may also be used to help provide variety in the diet.

Individuals with GA-1 will also require a “sick-day” plan, where protein from food will be eliminated for some time. Though, especially during the first few years of life, there is a low threshold for seeking emergency care during illness. Studies have shown the majority of neurologic injury occurs within the first few years of life. Many treating teams will loosen the protein restriction after adolescence, though this is highly debated, and most with GA-1 remain “on diet” and some medical formula for life.

Planning is Underway for Family Day 2023

Please mark your calendars on Saturday, September 24, 2023 for the next WeCare Clinic Family Day. In the past the event was called Family Genetics Disease Day. While the title of the event worked well in the past, the board of directors and staff want to include more than just the parents of children with rare genetic conditions. We recognize that grandparents and friends also help provide care for children with special health needs. Midwives are also welcome at the event. This year's WeCare Family Day will provide an opportunity to learn more about neurological conditions including seizure disorders, failure to thrive, and the founder's effect. There will also be time for families to fellowship with one another. For questions about the event, please call Matthew L. Hunt at 270-202-6603.



A Summary of Plain Insight Panel (PIP) Events

By: Jolene Schmucker, APRN

In July of 2022, WeCare Clinic in collaboration with local sponsors hosted a carrier screening day for anyone who wanted to be screened using the Plain Insight Panel. This panel is run by the Clinic for Special Children in Strasburg, PA. It is utilized both for screening purposes as well as diagnostic. Our goal was to increase screening in our area so that we can prepare couples who are carriers for conditions that could affect their children. The results are as follows:

- Autosomal Recessive Matches Incidence: 21 couples
- Disease-causing Mutations Found (Affective): 53
- Mutations Causing Carrier Status (Non-affective): 381
- Most Common Autosomal Recessive Match: Maple Syrup Urine Disease
- Top 5 of the Most Common Mutation Carried:
 1. Hereditary Hemochromatosis
 2. Maple Syrup Urine Disease
 3. Cystinuria
 4. Pompe Disease
 5. Galactosemia Duarte Variant



WECARE BOARD OF DIRECTORS:

- Mark Hoover
- Susan Jones, PhD, RN
- M. Eve Main, DNP, APRN
- Jerry Martin
- Marcus Nolt (Secretary)
Ph: (270) 886-6795
- Luke Shirk (Treasurer)
Ph: (270) 885-8210
- John Troyer
- Harvey Zimmerman (Chair)
Ph: (270) 475-4191
- Lawrence Z. Zimmerman (Vice-Chair)
Ph: (270) 886-5254

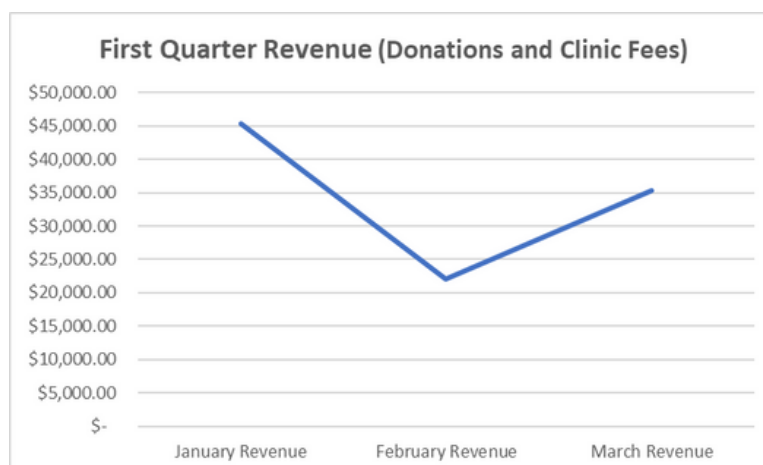
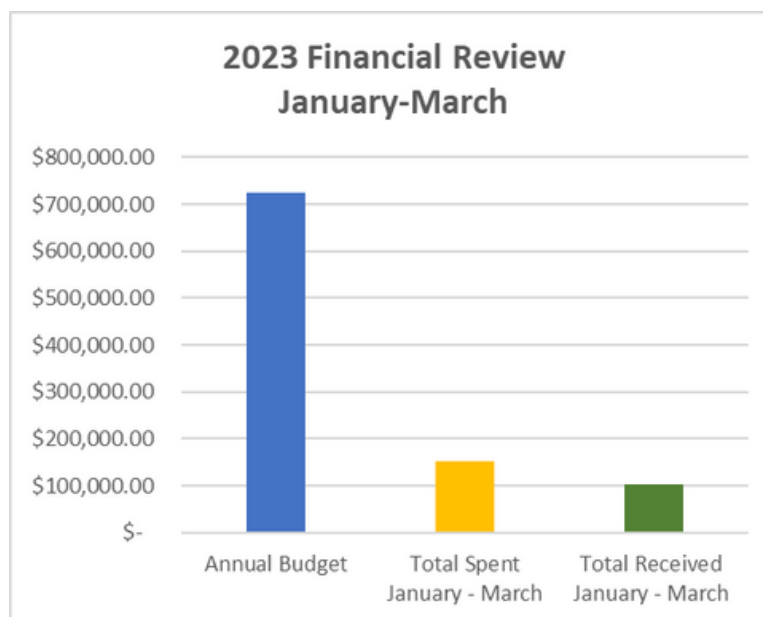
WECARE STAFF:

- Matthew L. Hunt, EdD
Executive Director
- Gregory D. Mock, MD
Medical Director
- Lesley Moshier, RN
Registered Nurse
- Jolene Schmucker, APRN
Nurse Practitioner
- Marlene Schmucker, RN, BSN
Registered Nurse
- Tammy Sisk
Office Assistant
- Renee Spivey, RN
Clinic Operations Manager
- Erin Teague, MS, RD/N, LD
Dietitian

More Funds are Needed As Number of Patients Continues to Increase

WeCare Clinic has collected \$102,702.73 in revenue through fundraising efforts and clinic revenue between January and March. Year to date expenses were \$153,089.91. WeCare Clinic is currently operating at a \$50,387.18 deficit. *More financial help is needed for operations for the clinic to make up the deficit for the first quarter of the year.*

Will you consider lending the clinic a helping hand through a tax-deductible donation to help us meet our budget? Funds can be mailed directly to WeCare Clinic at 775 Pembroke Fairview Road, Pembroke, KY 42266. If you have questions about donating to WeCare Clinic, you can call (270) 202-6603.



Contact Us

If you have any questions about supporting 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.



Upcoming Events:

WeCare Clinic Fish Fry Fundraiser

Date: April 28, 2023

Time: 4:00pm

Location: Bluegrass Sales Stables, 205 Trenton Tress Shop Road, Trenton, KY 42286

WeCare Clinic Fundraiser Auction

Date: June 9, 2023

Time: 6:00pm

Location: 524 S Fork Creek Rd, Liberty, KY 42539

WeCare Family Day

Date: September 23, 2023

Time: 9:00am - 1:00pm

Location: WeCare Clinic, 775 Pembroke Fairview Road, Pembroke, KY 42266

WeCare Clinic Fundraiser Auction

Date: October 6th and 7th

Time: Starting at 6:00pm on October 6 and Starting at 9:00am on October 7

Location: Bluegrass Sales Stables, 205 Trenton Tress Shop Road, Trenton, KY 42286

More Funds Needed for Renovation

To date, \$11,386.34 has been donated toward the renovation project. More funds are needed. We hope to get volunteer labor and donated building materials for the project. The board of directors has a goal of raising \$60,000 in 2023. The current facility is quickly becoming too small due to the expanding number of patients seen by WeCare staff.



To serve our ever-growing number of patients, we will add an educational room, small meeting room, and six offices in order to convert our existing offices to clinic rooms.

Will you consider a donation to the Renovation Challenge? Donations can be made by mailing them directly to WeCare Clinic at 775 Pembroke Fairview Road, Pembroke, KY 42266 with "Renovation Challenge" in the memo line of the check.

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

