

FALL 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](http://www.wecareforspecialneeds.org)

---

## Carrier testing... Why do it?

Many times when speaking to a group of people or when patients come to our clinic, Jolene and I get asked the same question... "Why should I do carrier testing? It will not change anything!"

I hope by reading the story of the Hoover family, who asked themselves the same question, you may think differently. Sometimes it is not about changing the outcome, it is about being prepared for the outcome. At WeCare Clinic, we strive to be proactive instead of being reactive.

I was sitting at my desk one afternoon in February 2022 when I got a call from a concerned mother about a toddler that was just not developing at the same rate as her other children. As we talked she was not sure if she was ready to have her daughter seen as a patient, but she also knew we would ask about carrier screening which she and her husband had not yet gotten. We talked through many options, and she thought it would be best to start with carrier screening as she was also pregnant at the time. We scheduled her and her husband for Plain Insight Panel (PIP) testing at the end of February.

On April 13th, we received a call from Clinic for Special Children (CSC) that the Hoovers were a match for Crigler-Najjar Syndrome Type 1 (CN1), which meant this could be passed on to their unborn child. Crigler-Najjar Syndrome Type 1 is a rare genetic condition which causes toxic levels of bilirubin in the blood. We spoke to the family and to CSC and formed a plan.

Continued on Page 2....

---

## INSIDE THIS ISSUE:

- Carrier testing...Why do it?
- 2023 Community and Family Health Awareness Day
- September Midwife Meeting a Success
- Presenting at the Translational Medicine Conference
- Does Your Community Want to Learn More about WeCare Clinic?
- Managing Picky Eaters: When Picky is a Problem
- Todd/Christian County Auction a Success
- Clinic Staff and Board of Directors
- 2023 Financial Review
- Upcoming Events
- Renovation to Begin Soon

## Carrier testing... Why do it? (cont.)

On April 20th, 2023, James and Arlene Hoover came to WeCare Clinic and were able to sit down to talk with Jolene, APRN, and with the staff at CSC, Dr. Carson and Karlla Brigatti, about the results of the PIP testing. During this visit the WeCare Clinic Staff and Clinic for Special Children were able to help the Hoovers with any questions and prepare them for what may come. Jolene set up newborn testing for specific variants found on the parent's carrier screening for the new baby and got paperwork to midwife Ann Moore, CNM. Jolene contacted the Vanderbilt Liver transplant team to alert them of a potential patient for management. James and Arlene were encouraged to speak with their adult siblings about PIP testing as well.



**By: Renee Spivey, RN**

After the Zoom video call with Clinic for Special Children, Karlla spoke with Jolene and I about what would be needed if the Hoover baby were born positive for CN1. As I mentioned above, CN1 causes a buildup of bilirubin in the body, which leads to jaundice and kernicterus. In some hospitals, they will put the patient under phototherapy lamps until levels come down and can send them home. Unfortunately, CN1 is much more severe and requires special phototherapy lights that are only built by one gentleman, Dr. Hendrik J. Vreman, at the Stanford University Medical Center in California.



**Dr. Hendrik J Vreman**



**Phototherapy Light**

Karlla Brigatti, at CSC, was able to give me Dr. Vreman's contact information, and I told him about the Hoovers and about WeCare clinic. He was able to get me the cost of the light and shipping, and I presented that to our board. The board decided that we could not take the chance of not having the light here at WeCare if the Hoover baby did test positive, so they voted to order it. Dr. Vreman then started the process, and a few weeks later we received the light in a suitcase with instructions and a book. Harvey Zimmerman and I put the light together with the wonderful help of Dr. Vreman on the phone if we needed him.

Travis Hoover was born on 8/7/2023 and a sample of his cord blood was sent to Clinic for Special Children. On 8/9/2023 while out of town, Jolene got the call that Travis Hoover was positive for CN1. Jolene coordinated the plan of care with the Vanderbilt Liver Team and the staff back at WeCare Clinic. The WeCare staff went to the Hoover home to draw bilirubin levels and to set up the phototherapy lamp. Because all this was in place Travis never had to go into the hospital. WeCare clinic and Vanderbilt Liver team are working together with the Hoover family for lab draws and checkups.

Continued on Page 3....

## Carrier testing.... Why do it? (cont.)

At a recent home visit with the Hoovers I asked, "What made you decide to do carrier testing? Could you imagine if you did not, and where we would be, and the difference it would have made?" Arlene said, "My sister had a child with a genetic condition, and we wanted to know if we were also carriers. I thought why not? We almost didn't but then decided too, and are thankful we did."

If Travis' parents did not do carrier testing and we were not prepared, what would have been different, you may ask. Travis would have ended up in the hospital with a lengthy hospital stay while they figured out what disorder he had and how to treat it. The light Travis needed could only be built by Dr. Vreman, and would have had to be built and shipped from California. Because of the Hoovers' gut choice to go ahead with carrier testing they were able to save Travis, themselves, and the community the stress and money of a lengthy hospitalization.



**Travis Hoover**

It took the collaboration of many people to bring about this outcome. I want to thank the staff at Clinic for Special Children for all their help in directing and guiding us along the way. I want to thank the Vanderbilt Liver Team for working with Jolene and our patient. Most of all I want to thank Dr. Hendrik Vreman for building and donating our first light. These lights cost around \$1200.00 plus \$300 to ship. We have been able to purchase the next light to have at the clinic in case another child is born with CN1.

When you are talking with your family and wondering if you should get carrier testing, I hope you think of the Hoover family and what we were able to do for them because they made this simple choice.

## 2023 Community and Family Health Awareness Day

Over two-hundred adults and children attended the 2023 Community Health and Family Day event held at WeCare Clinic on September 23. Presentations focused on malnutrition, founder effect, current and future genetic testing, and neurological conditions common in Plain Communities. The board of directors and staff would like to thank all the families that attended, the presenters, and all volunteers that made the day a special day for all in attendance.



## September Midwife Meeting a Success

On September 25, 2023, a group of 30 ladies, including midwives, midwife assistants, midwife apprentices, nursing instructors, members of the community, and WeCare staff members/board member, gathered under a tent on the grounds of WeCare Clinic for a fun morning of lecture, hands-on learning and lots of laughter and conversation. We were happy to again have OB staff from Bowling Green Medical Center as the presenters on the topics of Shoulder Dystocia and Placenta Placement. This presentation turned into a hands-on, interactive session. Our Dietitian, Erin Teague gave a very informative presentation on Nutrition for Expectant Mothers. This included nutrition recommendations for healthy expectant mothers and recommendations for mothers with metabolic disorders. After a pleasant lunch surrounded by lively conversation, we gathered again for story time with Jolene Schmucker, APRN. She shared on the importance of genetic testing and how knowledge of carrier status of parents before their baby is born is so helpful in the diagnosis and treatment of the newborn. She shared a recent example of how this played out in the lives of one of our local families. The parents decided to have Plain Insight Panel testing through Clinic for Special Children before their next baby was due. The PIP showed that both parents were carriers for a certain genetic disorder. When the baby was born, cord blood was sent to Clinic for Special Children for targeted testing for the disorder. The baby was diagnosed with the disorder within a few days after birth and treatment was started at home immediately afterwards, saving the family a huge hospital bill that could have resulted if diagnosis had come later. This story was followed by more sharing of experiences and suggestions, including how to discuss end of life care with families and communities with a child with a terminal illness.



By: Marlene Schmucker, RN, BSN

We all agree that this was one of the best midwife meetings WeCare has hosted. Gathering outside under the tent seemed to give the meeting a more informal feel and everyone felt free to ask questions and share experiences. We are planning our next Midwife Meeting for Spring 2024. Stay tuned for that date.





## Presenting at the Translational Medicine Conference

In August, Renee and Jolene made their way to Wooster, Ohio to give presentations during the 11th Annual Translational Medicine in Plain Populations Conference. This conference is a time when other genetic clinics that are part of the Plain Community Health Consortium and other close collaborators come together for two days while sharing pertinent information on genetic conditions and healthcare.



**By: Jolene Schmucker, APRN**

Jolene gave a presentation on “Old Order Mennonites”. She shared common disorders seen at WeCare Clinic in the Old Order Mennonite population such as MSUD, Glycogen Storage Diseases, Congenital Nephrotic Syndrome, Achromatopsia, Elliptocytosis, STRADA Deficiency, NPRL3 Epilepsy, PKU, CIPA, and Cystinuria. She also shared unique case studies that have occurred with patients at WeCare Clinic such as Hereditary Pyropoikilocytosis.

The room cheered when our new Crigler-Najjar baby was mentioned as this baby’s parents were identified as carriers before he was born, and all the necessary plans were set in place to test him right away. Crigler-Najjar is a genetic disorder that causes bilirubin to build up in the body, becoming toxic to the brain and resulting in brain injury, coma, or death. This child was able to avoid hospitalization and brain injury. It was a perfect example of how our clinics can work together to share information and save lives!

Updates on gene therapy were also shared with the other clinics. Achromatopsia (CNGB3) trial phases ½ are completed and show promising results in decreasing light sensitivity. AGTC is discussing with the FDA to schedule Phase 3. The most common side effect during clinical trials was ocular inflammation. MSUD gene therapy has been used in mice and cows. Clinic for Special Children is in the process of summarizing the preclinical data and will be submitting a clinical trial plan to the FDA. They will be using “mini cows” for the next level of preclinical testing.

---

### Does Your Community Want to Learn More about WeCare Clinic?

If so, contact us to schedule a Community Awareness Day. You will learn about the exciting happenings at WeCare Clinic, learn more about care provided at the clinic, meet clinic staff, and meet other families receiving care at WeCare Clinic.

If you have questions about scheduling a Community Awareness Day, call Harvey Zimmerman (270-475-4191), Lawrence Z. Zimmerman (270-886-5254), or Matthew L. Hunt (270-202-6603).

## Managing Picky Eaters: When Picky is a Problem

Most children go through what is considered a “picky” eating phase, often between the ages of 2-6. It is normal for children to test their environment and what they put in their mouth is one way to do so. For many parents, this can be a difficult time. They find themselves wondering if their child is eating enough, and what makes it a phase versus a problem?



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

For children, although they may skip a meal or be unwilling to try new foods, most are able to meet their needs over the course of a week. Keep in mind that a child’s serving size, should not be the same as a teenager or adult.

Picky eating can be a problem if:

- Your child willingly eats less than 20 different foods
- The foods your child accepts are all the same color, usually yellow/tan/white
- Your child struggles with different textures and only accepts one kind (crunchy or soft)

What can you do to help?

The best way to help right away is to remember the Division of Responsibility when it comes to food.

Parents decide: What, When, Where

- What foods are offered (a balanced meal with variety throughout the week, children need to see their parents model healthy eating too! Meals should include at least 1-2 accepted foods as well as small offerings of new or unaccepted foods)
- When foods are offered (regular meals and 1-2 snacks per day separated from meals by at least 1 hour)
- Where foods are offered (at the table, eating together with no distractions, in a pleasant environment. Limit discussion about how many bites are taken or if they are eating certain foods.)

Children decide: If, How Much

- If (they eat or even try a food. Even if it is not eaten, accepting new foods on their plate is a step in the right direction.)
- How Much (they eat – every taste is a win! Children do not need their plates piled high with foods, their servings should be  $\frac{1}{4}$  to  $\frac{1}{2}$  that of adults. If they ask for more servings of accepted foods, that’s OK! We want to encourage them to listen to their natural hunger cues. Children should not be made to finish their plates before a meal is done.)

Learning to eat (and enjoy!) a variety of foods can take time. If meals have become a battle, take a step back and evaluate. Try to make mealtimes pleasant – try a picnic or offer a different approach to meals such as breakfast for dinner or finger food night. If you have concerns contact a Registered Dietitian for help.

## Todd/Christian County Auction a Success

The board of directors and staff at WeCare Clinic want to thank everyone involved in the fundraiser auction that took place at Bluegrass Sales Stables on October 6-7, 2023. One hundred percent of the proceeds of the fundraiser auction benefited the operation of WeCare Clinic. Fundraiser auctions allow our staff to meet the special health needs of patients. If you are interested in hosting a fundraiser auction for WeCare clinic, contact Matthew L. Hunt at 270-202-6603.



By: Matthew L. Hunt, Ed.D.

### WECARE BOARD OF DIRECTORS:

- Mark Hoover
- Susan Jones, PhD, RN
- M. Eve Main, DNP, APRN
- Jerry Martin
- Marcus Nolt (Secretary)  
Ph: (270) 475-4128
- 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

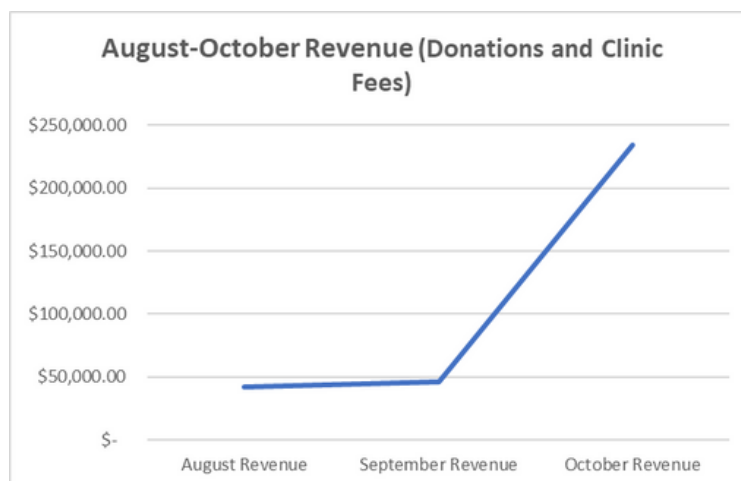
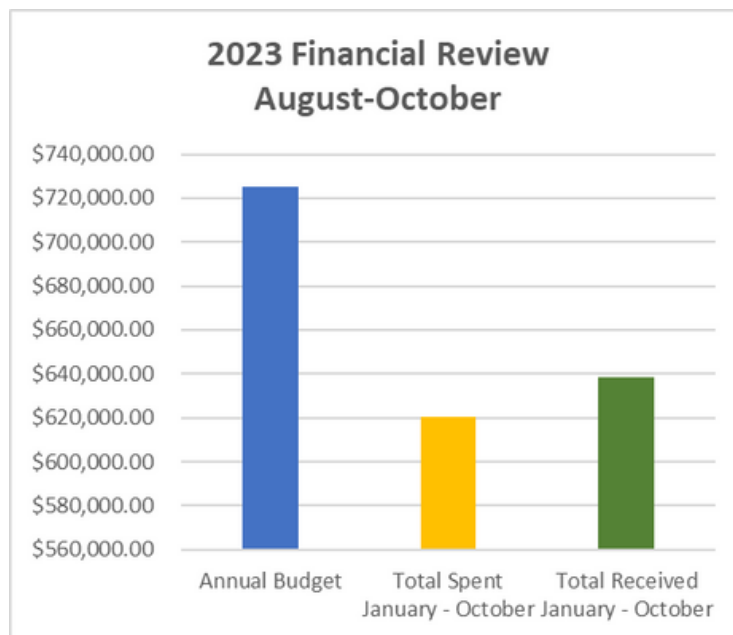
### WECARE STAFF:

- Matthew L. Hunt, EdD  
*Executive Director*
- Gregory D. Mock, MD  
*Medical Director*
- 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*

## Financial Overview

WeCare Clinic has collected \$638,689.13 in revenue through fundraising efforts and clinic revenue between January and October. Year to date expenses were \$620,381.32. WeCare Clinic is currently operating with a surplus of \$18,307.81. There are several large required expenses that will occur in November and December. More financial help is needed for operations for the clinic to meet the budget for calendar year 2023. Approximately 90% of the operation is funded by donations, while approximately 10% of the operation is funded by clinic revenue.

Will you consider making a tax-deductible donation to help us meet our operation needs? 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 Fundraiser

Date: Spring 2024

Time: TBD

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

WeCare Clinic Fish Fry Fundraisers

Date: Spring 2024

Time: TBD

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

WeCare Community and Family Health Awareness Day

Date: September 21, 2024

Time: 9:00am - 1:00pm

Location: TBD

WeCare Clinic Fundraiser Auction

Date: Fall 2024

Time: TBD

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

## Renovation to Begin Soon

The project was recently reviewed at the county-level, and we were advised that the renovation project would be considered as state-level project. We are currently working through those steps to gain state approval to begin the project. We are grateful for the support provided thus far. Through October 2023, \$41,693 has been donated toward the renovation project.



Harvey Ray Martin will serve as the contact for volunteer labor and donated materials. Harvey Ray's phone number is 270-265-5566.

Assistance is needed in the following areas:

Excavating

Insulation

Drywall

Windows

Footer/Laying Blocks

Roofing/Siding

Trim

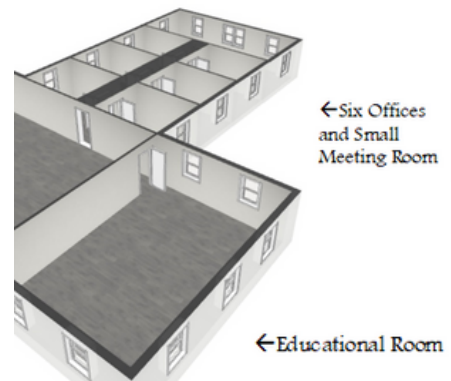
Doors

Framing

Flooring

Painting

Gutters



More funds are needed for the renovation. 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.

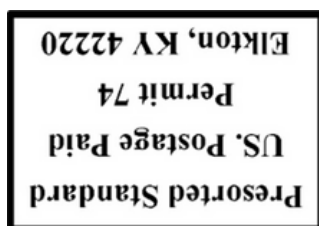
Mail to: Anabaptist Foundation, 55 Whisper Creek Drive, Lewisburg, PA 17837.

☐

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



WeCare Clinic - Medical Care for Special Needs  
775 Pembroke Fairview Road  
Pembroke, KY 42266

