

FALL 2024

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

Double the Money, Double the Impact

Families from over 14 states have received specialized genetic care at WeCare Clinic. Your previous financial support has allowed our dedicated staff to meet the healthcare needs of children and adults suffering from rare genetic conditions. WeCare Clinic has grown by leaps and bounds since first opening its doors in November 2020. I suspect the volume of patients and the states represented will increase in 2025 as it has every year. With each patient WeCare provides care for the expense for operation increases. Approximately 90% of the operating costs are paid by donations, while only 10% of the operating costs are paid by clinic revenue. More donations are needed as we close out 2024. Your tax-deductible donation will impact families in special ways.

It is not easy to double your money, but with the matching grant opportunity in November and December, it is easy to double your money and double the impact. We are grateful for the support of generous businesses. With their support over \$40,000 has been pledged as matching donations for the work at WeCare Clinic. I would like to challenge you to contribute toward matching their donation, so we are able to collect over \$80,000 before the end of the year. Our goal is to end 2024 without a deficit.

Donations can be mailed directly to WeCare Clinic at 775 Pembroke Fairview Road, Pembroke, KY 42266. with "Matching Grant" in the memo line of the check. If you have questions about donating to WeCare Clinic, you can call Matthew L. Hunt, Executive Director, at (270) 202-6603.

INSIDE THIS ISSUE:

- Double the Money, Double the Impact
- Phototherapy Lamps Made Close to Home
- 2025 Outreach Clinics
- A Mother's Journey with Postpartum Depression
- An Overview of Family and Community Health Awareness Day
- Fundraiser Auction is a Success
- Clinic Staff and Board of Directors
- Contact Us
- 2024 Financial Review

Phototherapy Lamps Made Close to Home

In the Fall of 2023, Renee Spivey, RN, Clinic Operations Manager, wrote an article regarding carrier testing, which focused on CN1. CN1 causes a buildup of bilirubin in the body, which leads to jaundice and kernicterus. Some hospitals put the patient under phototherapy lamps until levels come down and then send the patient home. Unfortunately, CN1 is severe and requires special phototherapy lights on an ongoing basis. The hospital lights are very expensive, and this creates a hardship for families needing a light at home. After years of rigorous research, Dr. Hendrik J. Vreman, from Stanford University in California, created a special phototherapy solution that is home based instead of hospital based. Dr. Vreman



By: **Matthew L. Hunt, Ed.D.**



Phototherapy Light

has dedicated years of his life to helping children across the globe, and he has ultimately saved many lives with his creation of the home phototherapy light. Due to Dr. Vreman's age, he desires to pass this knowledge to others to save the lives of children long after his life ends on this earth. Dr. Vreman came to WeCare Clinic this summer to educate the staff and board of directors about the phototherapy light and how to produce the lights. With the help of Dr. Vreman, Harvey Zimmerman has accepted the challenge to produce these lights for families. If you or a family member are in need of a phototherapy light, you may contact Harvey at 270-475-4191.

2025 Outreach Clinics

January 28 - Munfordville

February 26 - Flemingsburg

May 28 - Flemingsburg

July 23 - Munfordville

August 5 - Flemingsburg

October 21 - Smiths Grove

October 28 - Munfordville

November 11 - Flemingsburg

If you are interested in the upcoming outreach clinics or becoming a patient of WeCare Clinic, call 270-962-7383.

A Mother's Journey with Postpartum Depression

Childbirth, while being an exciting time for most, can be an exceedingly difficult and exhausting process. A lot of changes happen for females during this time. They go through a lot of hormonal, physical, emotional, and psychological changes throughout pregnancy. If you add a genetic diagnosis to the mix, it can add to anxiety in preparation of the unknown. After giving birth, a mother can experience many emotions from joy and pleasure to sadness and crying spurts. The feelings of sadness and emotional crying are called "baby blues" and they tend to go away after the first two weeks after mother delivers.



By: Renee Spivey, RN

Approximately, 1 in 7 women develop something much worse called Postpartum Depression (PPD). PPD severely affects women's ability to return to normal daily activities and will last much longer than "baby blues." The cause of PPD is unknown. It has been suggested that genetics, hormonal, psychological, and stressful life events play a role in development of PPD. Some females are at higher risk. Risk factors for PPD include having a depression diagnosis, experiencing a difficult pregnancy, having history of multiple miscarriages, lacking support at home, or already having a child with special needs.

In one study researchers found that over half of PPD in new mothers goes undiagnosed because of privacy issues. Postpartum Depression is profoundly serious and treatable! It doesn't mean someone will be on medication for the rest of their life. The most important thing is to understand PPD, and recognize when your loved one or friend may be in trouble and need help. PPD can result in death of not only mother, but baby as well, if left untreated.

WeCare staff knew we were missing something when a mother shared her lack of wanting to hold her baby. That's when we decided we must screen better for PPD. We ask all new mothers a list of questions that are private and only shared with our practitioner. The key is for husbands, family members, church members, and midwives to recognize signs and symptoms and get help. If you don't get help the first time, don't stop!

The symptoms of Postpartum Depression look a lot like major depression but happen after birth and up to a year or more after childbirth. Symptoms include depressed mood present most of the day, loss of interest or pleasure, difficulty sleeping or sleeping all the time, inability to concentrate, becoming very indecisive and agitated all the time. You may see weight changes either loss or gain. Every person is different. The mother will have a lot of guilt and feel worthless and could have recurrent thoughts of death and suicidal ideations. Please remember these females don't want to feel this way. They can't help the chemical imbalance going on in their body. So, the best thing you can do is talk about it and seek help.

WeCare Clinic strives to help the communities we serve in any way we can. While PPD is not a topic that is sunshine and rainbows, it is an issue that we need to be aware of. When talking to patients, community members, and midwives, this is a topic that came up. I was blessed

A Mother's Journey with Postpartum Depression (cont.)

to hear about a woman who was willing to share her story anonymously so people could understand what she went through many years ago. Her story brought me to tears as I felt her pain, need for help, and then her success. She shares her story to help other mothers, midwives, and families understand.

When I was asked to speak about a mother viewpoint of PPD I wondered how long I need to talk, 10 mins? 30 mins? Because in a nutshell of reality it was an awful experience! The memory is quite clear even though 25 years have passed.

Who is the most important person in a household? Mom! Where's Mom? Children have an uncanny sense of noticing the minute mom isn't around. What does Daddy say when he comes into the house and you're not in vision-where's Mom? That's good and right but what if mom feels like an empty cup and you find yourself saying this isn't what I expected.

Think back to being a little girl playing dolls. So tenderly you cared for it-surely a real baby would be even sweeter. You bought beautiful outfits dreaming of dressing baby dear. You just knew pacifiers are magic plugs. If need be, you would cheerfully rock on for miles while baby dear sleeps.

Baby arrives and whoosh go the dreams. Reality bangs on the door and you find yourself wondering where the girl is who friends called the life of the party. Now jokes irritated me, they weren't even funny. You would never meet me uncombed now I had greasy unkempt hair. I enjoyed cooking so why couldn't I think of a single thing to make. My easy-going husband scowled when I served boring tomato soup 5 days in a row. I yelled at him saying "be glad you even have food." Bed was a dreaded place, hearing the clock chime every 15 minutes. Not asleep! Not asleep! Never would I hate my husband, so why did I look at him and wonder-what does love feel like? This pretty, dark haired, rosy cheeked child we had prayed for-why did I hold her and think I can't even love you. My feelings were frozen. This was our third child and I never felt like this before. We had no clue what was going on.

The midwife had gone on vacation, so baby was eight weeks old till I had my six-week checkup, even though I had uterine infection from retained membrane. A fill-in midwife brought me medicine for that. Just before the midwife arrived, I bent to get a kettle from the cupboard... Snap! Went my back. I couldn't straighten up, so I hobbled to a chair. The midwife found me there in tears and I poured out my sob story of feeling so bad ever since birth. I'd felt that way the last 2 months of my pregnancy. With a smile she announced, "You have PPD." "What's that?" Is that diagnosis supposed to comfort me?

"Oh, it's common in new moms," she said. "It will go away again-sometime." With my hurting back I couldn't lie down so she shuffled the checkup to the next week. And...Left. I recalled my Mom saying to us girls (she had seven) once you have three children you need to become a sloppy housekeeper, or you'll go crazy. Although my frozen feelings couldn't feel love, my blank brain sure felt fear. Was I going crazy? Other Mothers serenely care for dozens of children without going crazy, so why couldn't I?

A Mother's Journey with Postpartum Depression (cont.)

I could hardly fall asleep, so you know that “blah, blah” of getting a nap while the baby naps like everyone tells you – felt like a punishment. I was angry at everything and one day when the baby once more cried every waking moment and the 2-year old just sneaked out of bed instead of napping – my top blew! I didn't want to harm my children. You may wonder where Daddy was. He was a busy dairy farmer and with a hot dry summer of 100 degrees he had to get the corn silage chopped. The community was small, consisting of twenty families, so maids were unavailable. My husband was baffled about my actions before, so when I confessed how this day had been he decided we need a doctor's help. But no! Not me – only crazy people need medicine and I'm not crazy, I'm just tired. My trusted sister, who listened to my woes, agreed with my husband and helped me figure out what to say to the doctor. Guess what? “Dr. Sweet” did not feel very sweet to me when he said “Oh, that's what happens when you have so many children so close together.” They were over two years apart and besides what could I do about that now? When I complained about hardly sleeping, he said it's okay not to sleep. That's when you work uninterrupted. Well, apparently this was all in my head. I felt extremely foolish. So, he sent us back home to drag through long days and weary nights. Two months later I read a story in Family Life magazine that described me perfectly. What a relief! You mean more moms feel this way? That lady recommended the book [This Isn't What I Expected: Overcoming Postpartum Depression](#) written by Valerie Raskin and Karen Kleiman. The town bookstore had to special order it. The first days I had read it, I read the book more than my Bible. It had lists of symptoms to figure out your feelings and I was shocked to check mark half or more of them! Such a comfort to be truly understood and be offered ways to overcome.

First of all, having a baby is a huge event! You've done something a man can't even do! So, admit your need to recover without being embarrassed. As a girl going with my Mom to see new babies, she would tell new mothers to take care. I thought that was just a nice way of saying goodbye, like have a nice day. But it is true. You deserve rest.

It's really important to listen to what you are telling yourself. You may be your worst enemy. I found myself muttering to the baby, “If you scream one more time, I'll scream with you.” A child would spill water and I would think, “I can't deal with one more mess.” While cooking meals the phone rang. I would say, “I'm falling apart; I can't do this.” Stop. You do not talk like that to others neither should you to yourself. Replace those thoughts with positive ones. It's encouraging to speak aloud to yourself and admit it is hard for you and the baby if she just cries. Tell yourself a mistake is not the end of the world, it will work out. You are doing the best you can. Focus on anything you do right, such as I singing “Jesus Loves Me” with the children.

“I changed baby's diaper and that helps her be comfortable even if she still cries.” If the day is really, really hard and you need to get away for a bit, put the baby in the crib and other children on the sofa or by the door to watch you as you take a walk around the house. No, they can't go with you this time. Cry if you need to, and of course, pray, then sing loudly as you pass by the window and wave to the watching children. Take several rounds till you calm down. If you're still out of control, is there someone who could come to help? Ask your husband to help you come up with a plan for what to do then.

A Mother's Journey with Postpartum Depression (cont.)

Nap time can be a challenge, yet we know sleep is refreshing. Have a box of special toys and books for the older children to have only when you're napping. Insomnia is common in PPD so if you can't sleep at least relax. Close your eyes and picture yourself walking along a lovely trail in a peaceful wood with a rippling brook and singing birds. But sometimes, for some of us, relaxing brings panic attacks. When the muscles relax, they give off lactic acid which can trigger panic attacks. To calm down focus on deep breathing- in through your nose and out through your mouth. Drink mint tea instead of coffee so there's no caffeine messing with your system.

If life just feels too tough, please, go to a doctor rather than just muddling on. I sure hope the first one is helpful, but if not scrape courage together and try another one. Back in my day there weren't many to choose from, so we just dragged on. One of my fears was "What if people hear I need medicine and they're unimpressed?" Why are we so worried about mood medicines? We don't scorn a diabetic for using insulin or if someone has high blood pressure. They would rather use medicine than have a stroke. Shrug off negative comments and assure yourself people will say ignorant stuff. They don't know how hard you tried. If a mother tells you she had baby blues too and she didn't go to the Doctor, merely smile with no comment. Baby blues don't compare to PPD. Blues can be helped with a great nap, a meal brought in, or the children going to Grandmas for the day. PPD reaches into your very heart. It affects all your thoughts and all your life. By and by you will feel better but how do you cope till then? We mothers are so used to caring for others that admitting we have needs feels selfish. It is not. Caring for yourself is a way of caring for your baby. In the morning, no matter if you slept well or not, wash your face, comb your hair, dab on perfume. It's okay if your dress doesn't fit right, nobody's clothes fit well after a baby. Read aloud a Bible verse you posted on the mirror. Not bothering to care for yourself has a domino effect on your entire day. When it comes to mealtimes use as much paperware as you can afford to avoid dishes. Line baking dishes with parchment paper to reduce hard scrubbing. Serve simple meals. Breakfast can be peanut butter spread on a piece of toast served on a napkin. Add a banana and presto no dishes. If your husband needs a more substantial breakfast maybe you could get him a breakfast sandwich together before he goes to work, and you and the children can have a relaxed breakfast later with peanut butter toast. Eat raw apples instead of cooking them into sauce or making apple goodies. Eat cereal as a dessert or have graham crackers and milk.

If you cook, make double the portions, one to eat and one to freeze or use later in the week. Put extra food in foil pans or lined baking dishes for less dishes later. An easy dinner is cooking chicken in the crock pot, serve on bread with BBQ sauce. After dinner, without washing the crock pot, add more water and rice for another meal. Make menu sheets with easy foods for each day of the week. It's okay to cut corners now, later you can cook with more variety.

For less laundry, hang up bath towels to dry and reuse. After all you just showered and are clean. Do you really have to iron clothes? Who will know if those wrinkles didn't just happen on the way to church? Do you have to fold clothes? Pant loops work great to hang on hooks, so do shirts and dresses. Allow yourself to be careless for now.

For easier housekeeping remove rugs, knick-knacks, flowers – everything you can possibly bear to tuck away. Remind yourself this isn't ugly – it's beautiful simplicity. Decide what area is most

A Mother's Journey with Postpartum Depression (cont.)

important to you. I didn't mind a messy sink as much as I detested a smelly bathroom, so any extra efforts went into bathroom cleaning. Who knows if you don't wash the bedding every week? But everyone will notice if they open the door and wonder where there's room to walk in. You still get to decide what really needs to be done.

There's one more person in the scenario that's just as important as you... Daddy! That man who holds your heart! He can feel overwhelmed by the strange new ways of his wife. Oh, he's a big boy he can care for himself, right? Yes, for a little while but when you have a chance to chat alone don't just focus on you and your terrible, horrible, not good, very bad day! It's relaxing for your brain to listen to HIS day HIS thoughts. If you need his help don't just vaguely say I need your support -tell him a hug would feel really good right now. Rather than saying "you never help", ask if he could put the children to bed this time or watch them 15 min. While you do something for yourself. Then thank him for it. Can you do something special for him? Maybe a back or foot rub, a glass of juice, or a special bedtime snack for just the two of you?

While you cannot rush recovery, you can have patience with yourself. After a while I felt better but just not like myself. It was like when you are swimming and heading up to the surface. Just before you break through, you wonder if your lungs will make it. I felt happy but still was below the surface.

Later you might look back on your journey and see how the ordeal formed you into a better person. During those hard days I wished older Mothers would see and reach out to me. Now I'm an older mother and wonder who is feeling bad and no one notices. Am I missing seeing that someone needing a helping hand? That's why you need to admit your needs and reach out to others for help.

If I may give a word to midwives, it is-be alert. You get to know us well and we're probably sometimes grouchy, but you likely have a good idea if someone is just having a bad day or if they are struggling to stay afloat, please don't be afraid to ask deep questions.

A short essay I liked about being a parent is this one: Being a parent is perhaps the only job that requires no training, no degree; gives no salary, allows no sick leave, and you can never ever say I quit! But it's a job with the best benefits. It's a job that changes you forever and shows you how deeply you are able to love. -Claudia G Lints

I hope this mother's story affects you and your family as it did myself. When I first heard it I read it over and over. If 1 in 7 women could have postpartum depression and half of those go untreated due to fear, we need to do better to support these women. I want to thank the brave woman and family for telling her story as it may save a mother, child, or entire family. PPD is not a permanent thing, it is temporary. Please seek help if you or your loved one is showing any signs or symptoms.

An Overview of 2024 Family and Community Health Awareness Day

On a beautiful September morning, families and speakers from Kentucky, Tennessee, and Pennsylvania arrived at WeCare Clinic. Over 150 attendees including families, staff, board members, speakers, kids, and those helping with children activities attended the event. We were delighted to host an event including world renowned doctors, researchers and speakers to provide us with an overview of MTHFR, HLA registry and SCID, Common Indications of Pediatric Liver Transplant, and a Brief Overview of Pediatric Liver Transplant Medical and Surgical Procedures. Delicious food was also provided at the event, while families were able to fellowship with one another. The speakers for the event included: Amy Albright, MS; Alanna Koehler, PhD; Sarah Kemme, MD; and Joseph Magliocca, MD. Planning is already underway for the 2025 Family and Community Health Awareness Day. Stay tuned to future newsletters as we share additional information closer to the event.

By: Matthew L. Hunt, Ed.D.



Fundraiser Auction is 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 4-5, 2024. Numerous hours were spent spreading the word about the auction, securing items for the auction, setting up the auction, cooking the delicious food, and selling the items to support the clinic. 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:

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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.

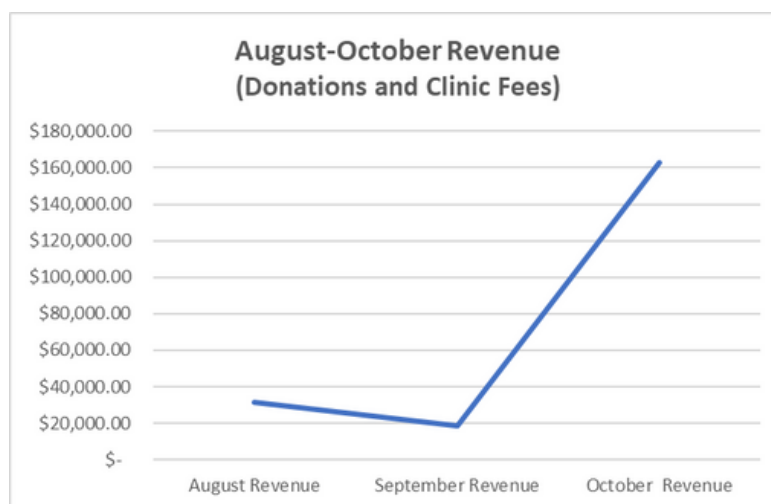
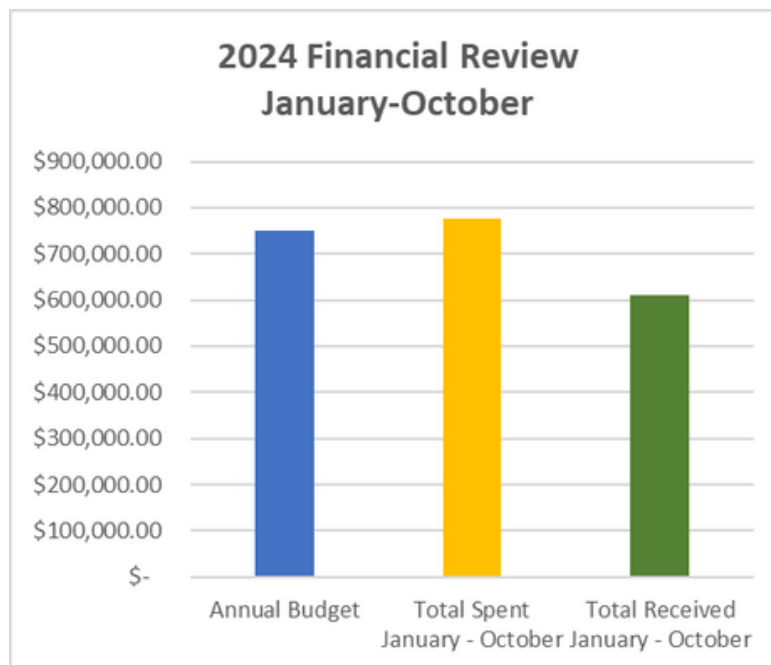
Financial Overview - January to October 2024

WeCare Clinic has collected \$609,058.13 in revenue through fundraising efforts and clinic revenue between January and October. Year to date expenses were \$777,378.08. WeCare Clinic is currently operating with a deficit of \$168,319.95. The larger than usual expense total includes a lot of one-time expenses related to the renovation. The renovation added much needed space to the clinic and allows us to host educational events at the clinic.



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.

By: **Matthew L. Hunt, Ed.D.**



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: _____

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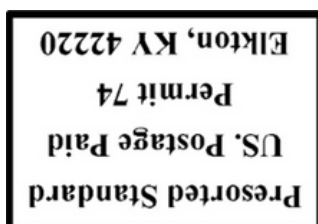
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If you do not wish to send donations directly to WeCare Clinic, anonymous contributions may be made through the Anabaptist Foundation. Make your check payable to Anabaptist Foundation with WeCare Clinic Fund on the memo line.

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.



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