

FALL/WINTER 2022

# 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

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## Do You Ever Wonder What WeCare Staff Provide Families?

WeCare Clinic staff strive to provide the highest quality of care for families, while also saving our patients and their families time and money. This means we work in collaboration with several hospitals to get good pricing on labs and to decrease travel when possible. We currently are working with hospitals at University of Michigan, University of Virginia, University of Pittsburgh, Vanderbilt University, University of Kentucky, Norton Children's Hospital, and Cincinnati Children's Hospital to manage the care of our patients with unique genetic conditions.

WeCare Clinic staff strives to build relationships with hospital systems where Plain community members feel there is room for improvement in culturally sensitive care. Our Nurse Practitioner has worked to decrease hospital stay of patients by helping facilitate after care for patients so they can be discharged sooner. The team at WeCare dedicates time to making referrals to doctors, specialists, and setting up diagnostic testing at locations that have affordable pricing. 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. 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.

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## Do You Ever Wonder What WeCare Staff Provide Families? (cont.)

Let me share a family story to help you understand what WeCare Clinic staff provide families.

When I started at WeCare Clinic, I met a family of eight, Marcus and Mary Louise Nolt and their six children. In the beginning I was seeing their daughter Sharon who is now 8 years old. She has Maple Syrup Urine Disease (MSUD) and received a liver transplant in 2019. We were working with Vanderbilt and the liver transplant team to draw labs and monitor her levels. Marcus and Mary Louise also have another child with MSUD. His name is Jared, and he is going to be 3 at the end of November. WeCare received the privilege of going on his liver transplant journey with him. I'm so excited to announce that Jared has received a liver and is recovering, but the journey to the transplant was not an easy one to say the least.



In June 2022, the Nolt family knew it would not be long before they would be ready to make that huge decision to place Jared on the transplant list, and that meant getting so much ready. I was in shock to hear the cost of a transplant alone had gone up from 2019 to over \$200,000. I could not imagine the stress that places on a family or community. Vanderbilt let the Nolt family do all Jared's pre-transplant blood work at WeCare. Vanderbilt quoted the cost of those labs around \$19,000. WeCare staff were able to provide lab services for approximately \$500 through a price agreement with a local hospital. Once Jared's labs were completed the Nolt's were ready to proceed, and he was placed on the transplant list on July 29th, 2022. The Nolt's received a call on August 30th that Jared went to top of the list. Then around 2:30pm on October 19th, they received the call that Jared had a liver!!!! They made the trip to Vanderbilt after he took a promised combine ride, and his brothers and sisters were taken to family and friends. Jared was in surgery at 5:30am on Oct 20th, and the transplant of a split liver was complete at 2pm. WeCare staff have been able to visit Jared and speak often to Marcus and Mary Louise as they are still in the hospital. He has been playing with his new tractor and combine but is still sore.



We continue our prayers for Jared and the entire Nolt family as this journey is not over. Also, we pray for the donor and his family that selflessly gave the gift of life.



**By: Renee Spivey, RN**

## A Spotlight on Classical Hereditary Hemochromatosis

The past several years have been filled with new and sometimes vague symptoms for Robert Troyer, a resident of Aroda, Virginia. The first symptoms that were identifiable were low testosterone and depression. This was treated for a period of time using natural supplements with limited success. As time went on, newer symptoms appeared such as weight loss and fatigue. This was soon followed by new onset of anxiety.



Robert's wife and loved ones knew something was not quite right. After much prayer, his wife reached out to WeCare Clinic to see if there was something we could do to help them find answers. After a thorough work up including lab work and genetic testing, our clinic was able to confirm a diagnosis of Classical Hereditary Hemochromatosis (CHH).

CHH is a genetic disorder that can occur on various genes causing an abnormal accumulation and storage of iron within the body's organs. This is damaging to the organs, causing diseases such as cancer, heart failure, hypogonadism (hormone dysfunction), diabetes, and thyroid disease. Symptoms are often vague, and many do not catch it until it has already caused considerable damage to the body. This disease does not usually manifest until age 50's with men and age 60's with women.

Treatment for this condition involves something called therapeutic phlebotomy (bloodletting). Blood is taken out of the body periodically based on storage levels of iron to prevent excess storage within the organs of the body. If there is an excess of iron being stored within the body, this may mean a few months of therapeutic phlebotomies every week. It also involves supportive care such as medications for diseases that are co-morbidities such as testosterone replacement therapy, diabetes management and treatment, and collaborating with specialists.

Since Robert's diagnosis, he has been on the path to healing. Genetic testing shows that his wife is also a carrier for CHH. This places their children at a 50% greater risk of having this condition. It is now important to test their grown children so that preventative monitoring and measures can be taken to avoid any future damage from iron accumulation.

For those with European ancestry, the prevalence of Hereditary Hemochromatosis is estimated to be 1: 227 and 10% of all Caucasians are carriers (NORD, 2022). If you would like to be screened for this condition, please contact our clinic for more information.



**By: Jolene Schmucker, APRN**

## Protein, The Basics

Protein is a macronutrient, one of the primary nutrients used by the body for fuel. Macronutrients are essential for health and daily function, which means our body cannot do without them.

Protein serves many roles within our bodies. The primary role is to provide structure with protein making up organs, muscles, hair, skin and nails. Protein is essential for growth and repair. It is also very important for metabolism, both as source of energy, and to help the body process other nutrients. Some proteins serve as hormones or as enzymes, helping other biochemical reactions in the body.



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

How much protein we need changes throughout life. During periods of growth, the body requires more protein. Infants need about twice the amount, per kilogram of weight, as adults do. During pregnancy, women have increased protein needs, about 70 grams per day. Illness and surgery can also increase your protein needs. If you have an Inborn Error of Metabolism, or kidney disease, you may need to adjust your protein intake.

The body cannot store extra protein, so eating more than your body needs will usually be converted to fat. Because it cannot be stored, spreading protein intake evenly throughout the day helps your body utilize it best.

Protein is most abundant from animal sources of food such as meat, fish, poultry, and dairy including milk, eggs, cheese, and yogurt. Animal sources have high biologic value, meaning our body utilizes them very well. Protein can also be found in high amounts in beans, legumes, nuts, and whole grains. Fruits and vegetables also have protein in smaller amounts. As with all nutrients, eating a variety of foods is the best way to make sure your body gets what it needs.

## A Recap of Family Genetics Disease Day - 2022

On September 24, 2022, WeCare Clinic hosted Family Genetic Disease Day on the clinic grounds. Due to the COVID pandemic, we had been unable to host this event for the past two years, so it was a delight to again gather and interact together in person.

Approximately 80 persons attended, including children. Attendees were from Allen, Butler, Calloway, Christian, Muhlenberg, Simpson, Todd, Trigg, and Warren Counties in KY and also from Clarksville, TN.



**By: Marlene Schmucker, RN,  
BSN**

Mark Loudon, PhD from Madison, Wisconsin was our main speaker on the topic of Communication Between Plain Families and Healthcare Providers. He stressed the importance of open communication with healthcare providers and Plain families. Patient impact stories were shared by Marlene Schmucker, RN and Mary Louise Nolt, local mother of children with MSUD.

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## A Recap of Family Genetics Disease Day - 2022 (cont.)

The stories were about interactions, positive and negative, between healthcare providers and Plain families.

Erin Teague, our dietitian, gave an informative presentation about the Role of Proteins in our Bodies and how that role is affected by certain genetic disorders. Throughout the morning, there were activities for the children including a treasure hunt, canvas painting, games, and water balloons. A tasty lunch was provided by community members followed by fellowship and conversations. We are excited about planning next year's event on September 23, 2023.



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### WECARE BOARD OF DIRECTORS:

- Mark Hoover
- Susan Jones, PhD, RN
- 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:

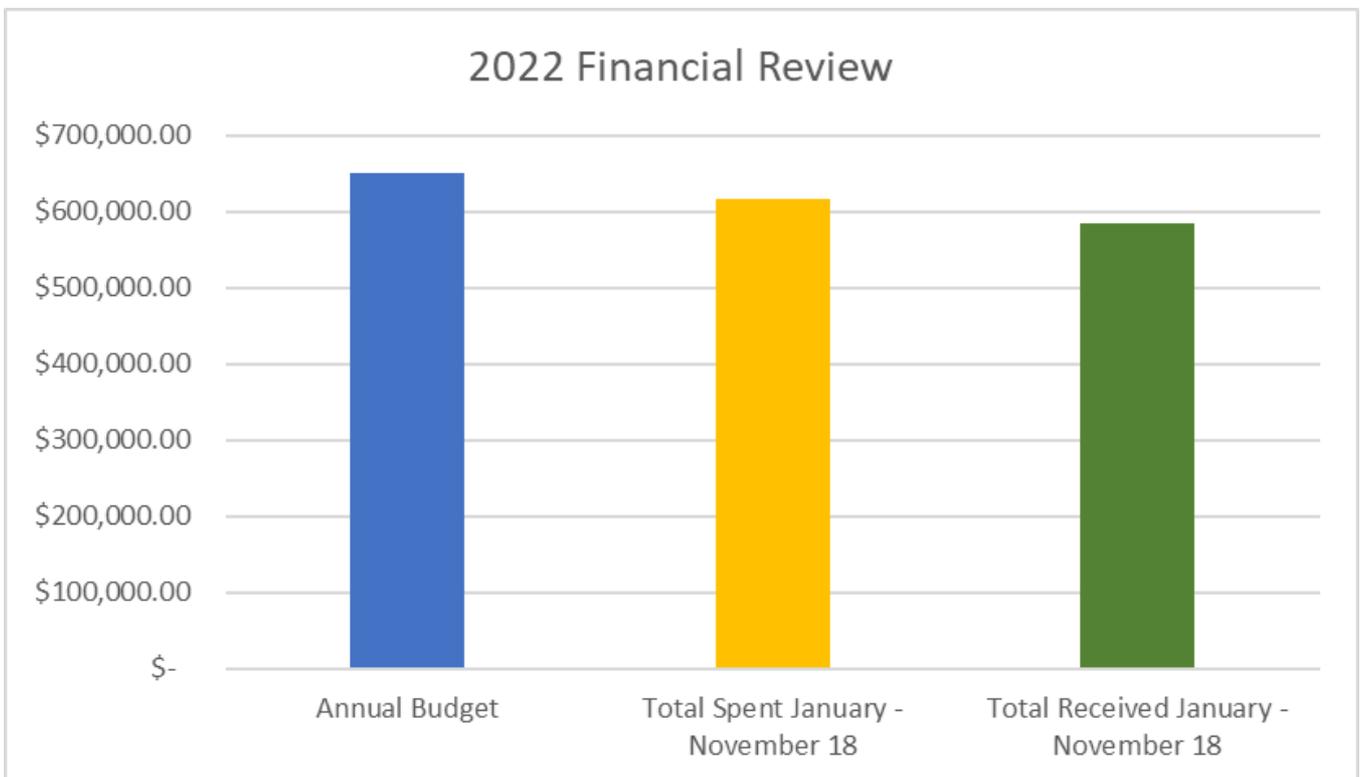
- Matthew L. Hunt, EdD  
*Executive Director*
- Gregory D. Mock, MD  
*Medical Director*
- Jolene Schmucker, APRN  
*Nurse Practitioner*
- Marlene Schmucker, RN, BSN  
*Registered Nurse*
- Tammy Sisk  
*Office Assistant*
- Renee Spivey, RN  
*Clinic Operations Manager*
- Erin Teague, MS, RD/N, LD  
*Dietitian*

## 2022 Financial Review

WeCare Clinic board of directors and staff are committed to improving the quality of life for families with genetic disorders through medical care, education, and research.

WeCare Clinic has collected \$585,206.05 in revenue through fundraising efforts and clinic revenue between January and November 18. Year to date expenses were \$615,674.32. WeCare Clinic is currently operating at a \$30,468.27 deficit. [More financial help is needed for operations for the remainder of 2022.](#)

[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 Fundraiser

Date: Spring 2023

Time: TBD

Location: Liberty, KY

### WeCare Clinic Fish Fry Fundraiser

Date: Spring 2023

Time: TBD

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

### 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: Fall 2023

Time: TBD

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

## Renovation Challenge

The board of directors and staff recently launched a Renovation Challenge with a goal of raising \$60,000. The current facility is quickly becoming too small due to the expanding number of patients seen by WeCare staff. To date, \$5,725.00 has been donated toward the renovation project. More funds are needed. We hope to get volunteer labor and donated building materials for the project.

We are grateful for the growth of the clinic, but we currently have multiple staff sharing offices, we are running out of storage areas for medical supplies, we do not have a break area for our staff, and do not have a meeting room for educational events for our families. During the renovation, we will add an educational room, breakroom, storage room, and six offices to the clinic to help our staff serve an ever-increasing number of patients.

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: \_\_\_\_\_

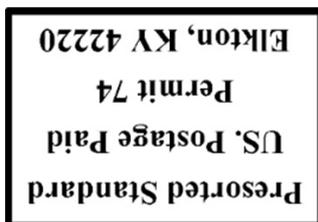
Date: \_\_\_\_\_ Check # \_\_\_\_\_ Amount: \_\_\_\_\_

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



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