SPRING/SUMMER 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

WeCare Clinic is Making an Impact

The WeCare Clinic staff and Board of Directors would like to share some exciting news with you. We are now available to see patients in the clinic Monday through Friday. We have had the privilege of providing care for patients in Iowa, Kentucky, Tennessee, and North Carolina. The patients from Kentucky and Tennessee are increasing rapidly.

We have had over 300 patient encounters through the first six months of the calendar year. We are providing care for patients with Nephrocerebellar Syndrome (Yoder Dystonia), Troyer Syndrome, Seizure Disorders, Congenital Ear Malformation, Familial Periodic Fever Syndrome, Prothrombin Thrombophilia, Hereditary Hemochromatosis, Maple Syrup Urine Disease without liver transplant, Maple Syrup Urine Disease with liver transplant, Congenital Nephrotic Syndrome, Pretzel Syndrome, Dextrocardia, Propionic Acidemia, GRIN2B-related neurodevelopment disorder, Glutaric Acidemia Type III (GA3), Achromatopsia, Hypercarotenemia, Cardiomyopathy, Immunodeficiency due to Ficolin 3 Deficiency, Down's Syndrome, Hyperglycinuria and several patients are awaiting a diagnosis.

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WeCare Clinic is Making an Impact (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.***

Patient Focus: Zimmerman Family

When our oldest son Matthew was born in 2013 we soon found out we would learn to care for a genetic condition called Maple Syrup Urine Disease (MSUD). We became familiar with a clinic called Clinic for Special Children (CSC) in Strasburg, PA that specialized in genetic conditions like MSUD. Dr. Morton's name was connected to this clinic, but we knew very little about him. While this clinic was miles away, we have had many clinic visits over the years and also sent regular amino acid tests to be tested at their lab. We took for granted that this clinic was already established many years ago and that we could receive care from a team that understood the condition that we were dealing with. You could tell they had experience in caring for MSUD. But is has not always been so. We must not forget how the older families have paved the way in caring for MSUD and other genetic conditions before these clinics were established and before the doctors had the knowledge that they do now.

While we had a good experience with CSC the distance was a barrier. We often wished for a clinic like CSC closer to home. The care that we also received from the geneticists and dietitians at Vanderbilt was good, but their setting just did not compare with what we experienced at CSC. Since these clinics are focused on genetic conditions found in the Plain Communities they can gain knowledge in a way that large hospitals cannot.

And now we have WeCare Clinic, a clinic modeled after CSC. This is a dream come true for many of us. In MSUD patients alone, we personally know of eight patients locally and the need for this clinic will continue to grow. We are grateful to the staff at WeCare Clinic for their dedication to these families dealing with genetic disorders. A lot of collaboration with other genetic clinics is done. It takes a lot of research, years of training and expensive equipment to be able to provide this specialized care. The care provided at these clinics would be in vain if the service would not be affordable, so please keep the donations coming! Your support and donations are needed and will be put to work to improve the quality of life for families with genetic disorders.

- Lawrence Z. and Linda Zimmerman and Family

What Are We Diagnosing at WeCare Clinic? A Spotlight on Tumor Necrosis Factor Receptor-Associated Periodic Syndrome (TRAPS)

Imagine having an illness from childhood with episodes of unexplained periodic episodes of fever with associated additional symptoms of muscle pain, abdominal pain, headaches, and skin rashes. The symptoms can vary greatly from one person to another. The duration of these episodes can last form a few days to several months. Usually, the diagnosis is very elusive with multiple tests being performed at different medical centers without a diagnosis being found. This scenario is typical for patients with a syndrome called TRAPS which is caused by mutations of the tumor necrosis factor receptor-1 gene that encodes for the 55-kDa receptor for Tumor Necrosis Factor. It is common for these individuals to reach adulthood without a diagnosis ever being made.

Signs and Symptoms: The signs and symptoms for TRAPS can vary significantly from person to person but nearly all will develop fever and abdominal pain. Most of the time these symptoms will last more than one week with some individuals experiencing significant inflammation.

A typical episode would include fever with associated symptoms of abdominal pain, headaches, joint pain, chest pain, muscle pain, stiffness, and tightness. The abdominal pain may be accompanied by nausea, vomiting, and diarrhea or constipation. The chest pain is very typical of pleurisy caused by the inflammation of the pleura which covers the lungs. Severe muscle pain can occur. The muscle pain may be associated with a rash which tends to start as tiny bumps that spread and then come together to form larger lesions called plaques. As the muscle pain progresses individuals will develop joint pain, though arthritis of the joint rarely develops.

Individuals with TRAPS can also develop conjunctivitis, which is painful inflammation of the membranes that line the inside of the eyelids. Other symptoms that occur in males is testicular pain and a higher rate of inguinal hernia than the general population.

The feared complication of untreated TRAPS is the development of something called amyloidosis. Amyloidosis develops in approximately 10 to 15 percent of individuals with TRAPS. Amyloidosis develops when a unique protein caused by the untreated inflammation accumulates in various tissues and organs of the body. One of the feared complications is when amyloid accumulates in the kidney leading to kidney failure.

Causes: TRAPS is caused by a genetic change (mutation) that usually is inherited in an autosomal dominant pattern (meaning only one parent needs to contribute a gene vs recessive where both parents need to contribute a gene for the disease to manifest). There are cases of a spontaneous mutation (where neither parent has the mutation but a spontaneous change in the gene occurs in the individual causing the disease). The risk is the same for males and females.

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What Are We Diagnosing at WeCare Clinic? A Spotlight on Tumor Necrosis Factor Receptor-Associated Periodic Syndrome (TRAPS) (cont.)

TNF is a protein that helps defend the body against infection and foreign substances. Tumor Necrosis Factor stimulates the body's inflammatory response to infection. Mutations in the TNFRSF1A gene results in defective Tumor Necrosis Factor Receptor 1 causing unchecked signaling of Tumor Necrosis Factor and excessive inflammatory response throughout the body.

The episodes of inflammation can be triggered or worsened by stress, minor trauma, and exercise. However, no specific trigger is necessary for the development of episodes.

Related Disorders: It is common for other inflammatory disorders to be considered as part of the evaluation for TRAPS. Many times, inflammatory arthritides such as psoriatic arthritis are misdiagnosed when the underlying problem is TRAPS.

Diagnosis: The diagnosis of TRAPS is made based upon a thorough clinical evaluation, history of symptoms consistent with TRAPS, and blood tests which show signs of inflammation. The diagnosis of TRAPS is then confirmed by genetic testing which can identify mutations in the TNFRSF1A gene.

Therapies: TRAPS is frequently treated with high doses of corticosteroids (prednisone) which often controls the episodes of inflammation. Unfortunately, the effectiveness of prednisone often decreases over time plus there are significant health risks with the long-term us of corticosteroids. Nonsteroidal anti-inflammatory drugs such as ibuprofen can be beneficial in treating fever, but unfortunately are not effective in controlling the other symptoms of TRAPS. Newer therapies with drugs targeted at the Tumor Necrosis Factor Receptor-1, which inhibit the actions of tumor necrosis factor, are proving to be effective. Other targeted therapies with IL1 cytokine inhibitor, canakinumab, is proving to be highly effective in controlling attacks of inflammation associated with TRAPS. Another investigational drug is the IL-1 inhibitor, anakinra, which has now been used to treat TRAPS with success. The use of these drugs is well tolerated: the most frequent reported adverse events are infections. Ongoing research is continuing.

For further information about this disease the National Organization for Rare Disorders is an excellent source of information.

- Dr. Gregory D. Mock
Medical Director

WeCare Clinic
Medical Care for Special Needs

WECARE STAFF:

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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 RJ996l.

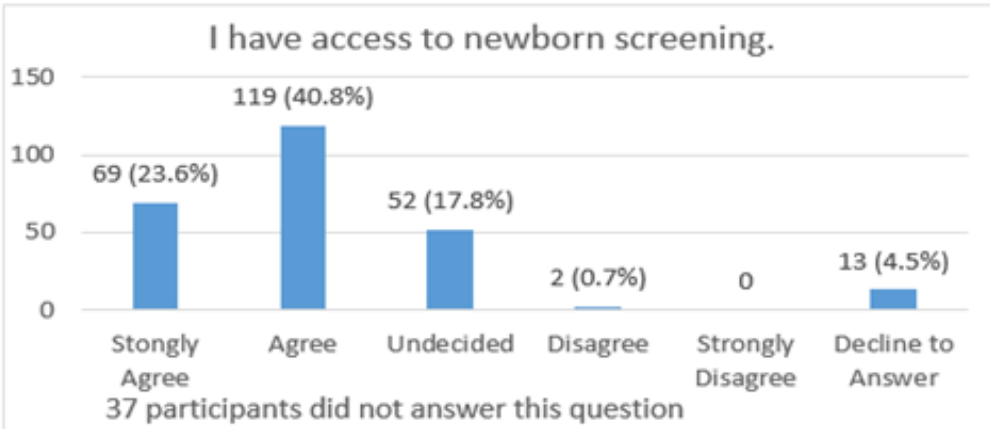
If you shop on Amazon, you can support WeCare Clinic. The AmazonSmile Reward Program will donate a proceed of each purchase you make to the clinic. Simply visit AmazonSmile to link your account to WeCare Clinic.

Newborn Screening Research Project

The purpose of this study is to understand the newborn screening needs, experiences, and concerns of the Kentucky Amish and Mennonite communities. We appreciate the participation in the study. We received responses from 292 participants. These participants were made up of 41.7% Old Order Amish, 36.0% Old Order Mennonite, 13.4% Conservative Mennonite, 4.5% New Order Amish , and 3.8% other. The majority of the participants live in Todd and Christian county with 16.8% and 16.4% respectively.

We found that the majority of participants have some or a little knowledge of newborn screening at 78.4% total. Only 12.7% had no knowledge or had never heard of newborn screening. The majority (59%) also felt that newborn screening was either very important or important in preventing disability or death for their family.

Access to newborn screening is an important issue and we found that 23.6% strongly agree and 40.8% agree that they have access to newborn screening with 69.5% reporting that their children had received screening tests. There were several reasons children did not receive newborn screening. These include too expensive, did not know about it, travel to screening was too difficult, the healthcare provider did not offer it, discouraged by the healthcare provider or others, concerns with follow-up testing or medical care if the baby failed the test, family does not believe in it, and other. Those who answered other provided many written explanations such as they did not feel it was necessary as they had not had any issues so far or did not have genetic disease in their family history. Thank for your support and participation.



-Missy Travelsted, DNP, APRN, FNP-C
Primary Investigator

Upcoming Events:

Family Genetics Disease Day
Date: Saturday, September 18, 2021
Time: 9:00am-4:00pm
Location: WeCare Clinic, 775 Pembroke Fairview Road, Pembroke, KY 42266

Fairview Fundraiser Auction
Date: Friday, October 1, 2021 and Saturday, October 2, 2021
Time: Main Auction Begins at 6:00pm on Friday and Main Auction Begins at 9:00am on Saturday
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, but more help is needed to fund the clinic throughout 2021. Approximately 70%-75% 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. Please consider helping us reach our fundraising goal of $650,000 for the operating expenses in 2021.

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.

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