WeCare Clinic - NEWSLETTER

Medical Care for Special Needs

775 Pembroke-Fairview Rd. Pembroke, KY 42266

Fall 2019

"Our mission is to improve the quality of life for families with genetic disorders through medical care, education, and research."

Firstly, thank you to all those who came out to the clinic and participated in our Genetic Screening Day in May. It was a huge success as the clinic's first formal work in providing information and care to the communities around us. If you or your family are still waiting for the results from the screening day, please be patient. The Clinic for Special Children in Strasburg, Pennsylvania is working as efficiently as they can with the large volume of samples they have. The staff at WeCare is eager to continue working with the communities in the area and are proud to announce some upcoming events in the fall! See attached for information about these events as well as some information regarding the two diseases that will be focused on during the Family Genetic Disease Day. As always, thank you for your continued support for our clinic.

Upcoming Events:

2nd Annual Family Genetic Disease Day

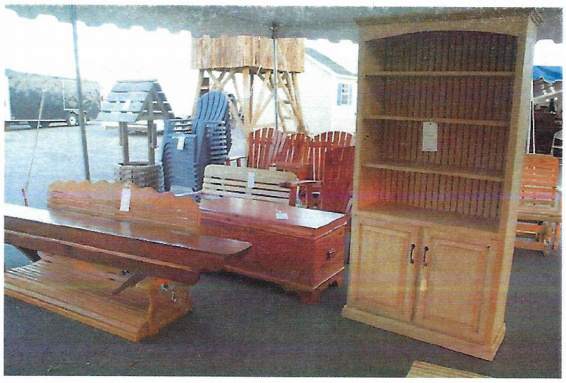
Saturday, September 14th
WeCare Clinic
See inside for details

3rd Annual Fundraiser Auction For Special Needs Children

Friday, October 4th & Saturday, October 5th
Bluegrass Sales Stables
See inside for details

2nd Annual Family Genetic Disease Day

Saturday, September 14 at the WeCare Clinic. The WeCare Clinic is continuously looking to offer educational sessions throughout the year. Educational events such as this allow the clinic to learn more about the genetic conditions present in this area, provide information to families who are managing genetic health concerns daily, and allow the clinic to act as a venue to share and hear the best practices and methods for providing care for those with genetic conditions. This event will include talks from Dr. Morgan, Dr. Weisner, and Karlla Brigatti, genetic counselor. The basis of genetics will be discussed as well as various genetic diseases with an emphasis on Propionic Acidemia and Lynch Syndrome. Additionally, information on carrier testing and immunizations will be provided. This event will be a great way for families who have or suspect genetic conditions to come together as a community. Activities for children will be provided throughout the day. Learn more by attending the 2nd Annual Family Genetic Disease Day on September 14th 9:00am at the clinic location.



3rd Annual Fundraiser Auction For Special Needs Children

The auction will be held at the Bluegrass Sales Stables at 205 Tress Shop Rd. Trenton, KY 42286 on Friday, October 4th from 4pm-8pm amd all day Saturday, October 5th. Dr. Strauss, from Clinic for Special Children, will be speaking Saturday at 11am. This auction's net proceeds will go to the WeCare Clinic.

There will be a catfish fry for Supper on Friday night. On Saturday, Breakfast is from 6am-9am and Lunch is from 10am-3pm. A bake sale will also be held on both days.

Items currently for sale at the auction include: Handcrafted Quilts, Theme Baskets, Musical Clocks, a new Roll Top Oak Desk, 4 pc. Cherry Bedroom Suite, Mini Storage Buildings, a 24x32 Pole Barn Built on Your Level Site, Household Furniture, Shuffle Board, Corinthian Bells Wind Chime, Garden Mums and Shrubs, Poly & Wood Lawn Furniture, Power Horse pressure washer, Milwaukee Power Tools, Dewalt Power Tools, and many more items.

What is propionic acidemia and how does it affect Plain communities?

Propionic acidemia is a genetic disorder in which the body doesn't make enough of a certain protein called an enzyme ("propionyl coA carboxylase"). This enzyme normally helps the liver break down certain amino acids (the building blocks of proteins) including valine, methionine, isoleucine, and threonine. When the body doesn't break these down properly, abnormal amounts of propionic acid build up in the blood. This causes a child or even an adult to become very sick if they get even a minor illness like the flu. Vomiting or poor feeding in a baby is often the first sign of the disease. Babies are all tested for it, though, by sending the heelstick test to the state laboratory for newborn screening after a baby is born.

The form of propionic acidemia that is frequent in Amish and Mennonite populations is usually milder than most cases, but there's still a big risk of children or adults getting severely ill and also a 30% risk to develop cardiomyopathy (an enlarged heart that doesn't pump well). However, people can go for years and not get sick, so they may not realize just how serious the diagnosis is and how important it is to get regular care from a doctor who knows how to monitor and treat people with the disease.

A child has to inherit a mutation from both unaffected parents in order to be affected by the disease. The parents are called "mutation carriers" because they have one normal gene and one that has a certain mutation ("the PCCB c.1606A>G; Asn536Asp" mutation in Plain populations). If both parents are carriers of this mutation then the child has a 1 in 4 chance of being affected by propionic acidemia.

The current treatment of propionic acidemia is a special low-protein diet that has just enough valine, methionine, isoleucine, and threonine in it for a child to grow or adult to stay healthy. If a person with propionic acidemia gets the flu or another viral infection, they often have to be put in the hospital to get sugar-water through a vein to keep them from getting very sick. Many patients with more severe cases of propionic acidemia need to have a liver transplant, and this helps a lot but doesn't completely cure the disease. There is a major need for better treatment of propionic acidemia. New treatments being researched for a similar condition, methylmalonic acidemia, might also work for propionic acidemia. One of them is called "messenger RNA medicine," which is like gene therapy but instead of DNA, a related biochemical called RNA is used to trick liver cells into making the correct protein.

We invite all families who are affected by propionic acidemia to come to Family Genetic Disease Day on Saturday, September 14 to hear Dr. Thomas Morgan, a member of the WeCare Clinic Board of Directors and a medical biochemical geneticist at Vanderbilt University Medical Center, talk all about propionic acidemia and the research to find a better treatment for this serious genetic disease.

What is Lynch syndrome and how does it affect Plain communities?

Lynch syndrome is a genetic disorder that puts someone at high risk to develop colon cancer and many other types of cancer as well. Adult patients with Lynch syndrome may develop cancer of the almost any part of the digestive tract, upper urinary tract, and even the brain and skin. Women with Lynch syndrome have a high risk of cancer of the ovaries and endometrium (lining of the uterus). Variations in any of several genes involved in repairing DNA (such as MLH1, MSH2, MSH6, PMS2, or EPCAM) can increase the risk of developing Lynch syndrome.

To the best of our knowledge, Plain populations are NOT at higher risk than the general population for Lynch syndrome or other cancers. However, since Amish and Mennonite parents tend to have more children than parents in the general population, if one ancestor had Lynch syndrome then a very large number of the descendants may be at risk for it. If one of your parents had Lynch syndrome, then there's a 50% chance that you will have it, too.

Because colon cancer in Lynch syndrome starts out as a tiny growth called a polyp in the colon, it is possible to prevent cancer from forming by taking out the polyp. That requires a colonoscopy, in which a scope has to be inserted into the colon to look inside and snip out any polyps. If there is a known genetic mutation in a Lynch syndrome gene in a family, then each person at risk can easily be tested to find out if they inherited it or not. If not, then the person does not have Lynch syndrome and does not need any special cancer screening beyond what is done in the general population.

Since we know that some Plain families in the region surrounding the WeCare Clinic may have Lynch syndrome, there is a need for WeCare to identify everyone who might want to be tested for this. Once everyone who is interested in getting more information about testing signs up with WeCare, then it will be possible to organize a research project with Vanderbilt to help everyone get access to genetic counseling and testing. We invite everyone interested in this topic to come to Family Genetic Disease Day on Saturday, September 14 to hear Dr. Thomas Morgan and Dr. Georgia Wiesner from the Vanderbilt Cancer Center to talk in more detail about Lynch Syndrome as well as the importance that everyone gets to know their own family history of all types of cancers.

Thank you for making a new donation to WeCare Clinic.

Make your check payable to: WeCare Clinic

Mail to: WeCare Clinic, 775 Pembroke Fairview Rd. Pembroke, KY 42266

Donation Made by:_____

Address:_____

City:_____ **State:**_____ **Zip Code:**_____

Date:_____ **Check #**_____ **Amount:**_____

☐ **Check here if you wish to receive a tax-deductible receipt at the end of the year.**

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, 1245 Old Route 15, New Columbia, PA 17856

The clinic board would like to thank everyone from the different communities for the support that was shown and a willingness to work together to establish this special needs clinic.

WeCare Clinic — Medical Care for Special Needs

2nd Annual Family Genetic Disease Day

September 14th, 2019 at 9:00AM

775 Pembroke Fairview Road, Pembroke, KY 42266

Registration Form

Name: _____

Address: _____

Phone: (___)_____ Fax/Email: _____

Participants Name	Age	Diagnosed or Suspected Genetic Disease (circle one)	If yes, what genetic disease does participant have?
		Yes No	
		Yes No	
		Yes No	
		Yes No	
		Yes No	
		Yes No	
		Yes No	
		Yes No	
		Yes No	
		Yes No	

Do you or any family members attending have food allergies or specific food requirements? (If yes, please describe)

_____

_____

For questions, feel free to call (270)-962-7383 or (270) 776-3552. We look forward to seeing you on September 14th for a great day of learning and discussion regarding genetic conditions. Check in will begin at 8:30 am.

Return registration form by August 31st to WeCare Clinic. 775 Pembroke Fairview Rd. Pembroke KY 42266