The Community Health Clinic
A NEWSLETTER FOR THE CHC
SPRING/SUMMER 2024

GENETIC CAUSES FOR SEIZURES (EPILEPSY)

WHEN IS IT IMPORTANT TO INVESTIGATE THE SEIZURE DISORDER FURTHER?

Rhonda Anderson, RN, MSN, FNP-C; Nicole Bertsch, MS, CGC

This topic for the newsletter is dedicated to a very special little girl who earned her angel wings too early due to a genetic seizure disorder – Alysa R. Beechy 2/24/2023-7/3/2023

Rhonda Anderson, RN, MSN, FNP-C

Nicole Bertsch, MS, CGC

Epilepsy is a condition that causes people to have repeated seizures and is the fourth most common neurological disorder in the world. These seizures are caused by abnormal electrical activity in the brain. Seizures can make you have convulsions (sudden shaking episodes), pass out, or move or behave strangely. Epilepsy can start at any age. There are many different kinds of seizures. Each can cause different types of symptoms. Most seizures last only a few seconds or minutes. Some happen sporadically and some happen multiple times per day.

Children who have "tonic-clonic" or "grand mal" seizures often pass out, get stiff, and then have jerking movements of upper and lower extremities. Other types of seizures cause less dramatic symptoms. For instance, some children have shaking movements in just one arm or in a part of their face. Other children suddenly stop responding and have a blank stare called "absence seizures" or "petit mal seizures."

Sometimes, people can tell that they are about to have a seizure. They have a certain feeling or smell just before the seizure. This feeling or smell is called an "aura." Sometimes seizures can be triggered by fever, by illness, or sometimes by nothing at all.

Some disorders can mimic seizure like activity. Hyperekplexia or an exaggerated startle reflex, or an anoxic seizure which is a non-epileptic event that causes loss of consciousness due to a vagal response followed by tonic-clonic movements of the limbs, are some examples.

If you think your child has seizures, a doctor will usually do tests to learn more about the seizures and to check whether they are caused by epilepsy (not all seizures are caused by epilepsy). Your child will probably have an:

- EEG – An EEG measures electrical activity in the brain.
- MRI or CT scan – These tests create pictures of the brain.

Epilepsy is not a specific disease, but rather a tendency to have recurrent seizures over a period of time. Seizures that occur when a child has a fever, head injury, or after taking drugs often do not recur and are not considered epilepsy. In addition, what appears to be a seizure may actually be something else (i.e., breath holding spell). Having one seizure does not mean that a child has epilepsy. Many clinicians require a child to have more than one seizure before diagnosing epilepsy.

Epilepsy in children is usually treated with anti-seizure medication. These medications cannot cure epilepsy, but they can help prevent seizures. There are many different anti-seizure medications. The right one for your child will depend on the type of seizures they have.

If a child is determined to have epilepsy, genetic testing can be done to investigate the underlying cause. About 30-40% are caused by a genetic condition. Finding a genetic diagnosis can guide treatment (i.e. which antiseizure medications may be effective), make doctors aware of other health problems that might develop, and provide

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ABOUT THE COMMUNITY HEALTH CLINIC

The Mission of the Community Health Clinic (CHC) is to provide excellent and affordable medical care consistent with the needs of the Amish, Mennonite and other rural northern Indiana communities with a focus on individuals and families with special health care needs. The CHC embraces, incorporates and promotes participation in research to advance medical knowledge and improve care.

The Community Health Clinic

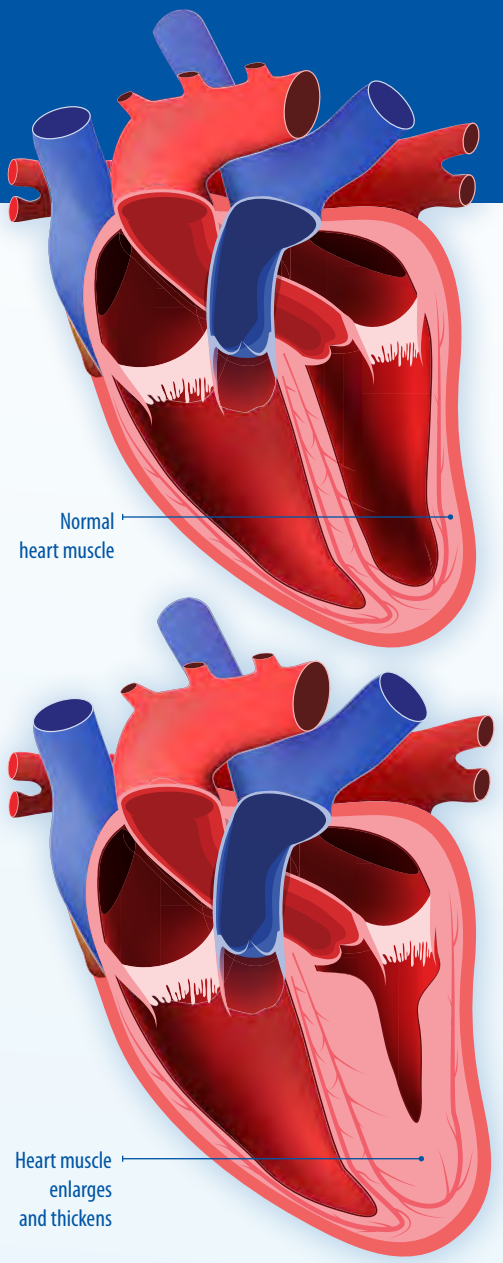
The CHC was founded in collaboration with the local Amish and Mennonite communities. With the endorsement of the Free Will Committee, we established a Board of Directors in 2008. Careful planning and generous community support allowed us to begin seeing patients in 2013, offering high quality care at a greatly reduced cost to our families. We are open to the public, with a particular focus on serving the Plain communities. Currently, more than three fourths of our patients are from the Amish or Mennonite churches. Much of our annual budget comes from donations and fundraisers from the local community.

Now celebrating our 11th year of service, we have provided specialized services for over 21,000 patient visits for both children and adults with rare genetic and metabolic disorders. Most of our patient families come from Indiana and Michigan, but we have served both Plain and non-Plain families from 21 different states and some foreign countries. Our clinic provides medical management of complex diseases and offers genetic counseling, dietary services, and newborn screening. We collaborate with regional hospitals and health systems and routinely work with them to provide follow-up services to our patients in need. Our patient population in Michiana continues to grow, both near our clinic and in outlying communities as well. Throughout the year, we now see patients in outreach clinics as far north as Clare, Michigan and south to Paoli, Indiana and Northern Kentucky.

The disorders that affect the Plain communities are not unique to them; what we learn through research and care of our patients benefits all. Education is a critical part of our mission for families and clinicians. The Community Health Clinic collaborates with physicians and medical researchers across the country and around the globe to share our expertise, learn from others, and help ensure a better future for all those affected by rare disorders. We are grateful for your advocacy and support and are truly blessed to do this meaningful work.

From left to right: Jared Beasley, MBA, RN, Executive Director and Zineb Ammous, MD FACMG, Clinical & Biochemical Geneticist, Medical Director

FAMILIAL HYPERTROPHIC CARDIOMYOPATHY, TYPE 4 (HCM4)



What is it?

Hypertrophic cardiomyopathy (HCM) is a heart condition characterized by thickening (hypertrophy) of the heart (cardiac) muscle. Thickening usually occurs in the muscular wall that separates the lower left chamber of the heart (the left ventricle) from the lower right chamber (the right ventricle). This can lead to the heart having difficulty pumping blood to the rest of the body and also to abnormal heart rhythms (arrhythmia).

How common is HCM?

HCM is the most common genetic heart disease in the United States and affects at least 1 in 500 people. *MYBPC3* gene mutations cause up to 30% of genetic HCM. When HCM is caused by a *MYBPC3* gene mutation, it is known as HCM type 4 (HCM4).

What causes HCM4?

A mutation or DNA change in a gene called *MYBPC3* causes an abnormally short or altered cardiac MYBP-C protein that does not work as well. This protein plays an important role in the structure of the heart muscle, so when a person inherits one mutated copy of the *MYBCP3* gene, he or she is at risk to develop HCM4.

How is HCM4 inherited?

HCM4 is inherited in an autosomal dominant manner. This means that one mutation is needed in one of the two copies of the *MYBPC3* gene for a person to be at risk to develop HCM4. A person who has a mutation in one copy of the *MYBPC3* gene has a 50% chance to pass that mutation on to any of their children (regardless of whether they are boys or girls or whether the mutation is in Mom or Dad). The siblings of a person with HCM4 also have a 50% chance to have the *MYBPC3* mutation.

When two people who both have one *MYBCP3* gene mutation have children together, there is a 25% chance with each pregnancy for a child to inherit two *MYBCP3* gene mutations (one from each parent). This leads to no working copies of the *MYBCP3* gene and very little functioning MYBP-C protein in the heart. Most babies develop very severe heart disease at a young age (within a few months to a few years after birth). Therefore, we recommend that the spouse of anybody with a known *MYBCP3* mutation get testing themselves (even if there is no known family history of heart problems or a *MYBCP3* mutation).

What is the treatment for HCM4?

There are no therapies that "cure" HCM4 but there are many treatments that improve symptoms and decrease the risk of complications. These include different types of medications, procedures to correct abnormal heart rhythms, and even heart transplant in very advanced cases. The earlier treatment can be started the better the outcome. Symptoms of HCM4 are monitored using an echocardiogram (ECHO), which is an ultrasound of the heart. An EKG can also be done to look at the heart's rhythm.

Who should have genetic testing for HCM4?

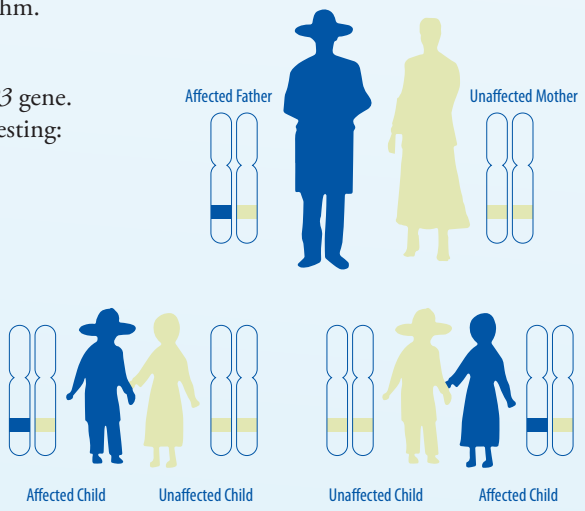
Genetic testing is performed to see whether a person has a mutated copy of the *MYBCP3* gene. Anyone with a personal and/or family history of the following should consider genetic testing:

- Hypertrophic cardiomyopathy (HCM) diagnosed on echocardiogram
- Previous genetic testing that is positive for a mutation in the *MYBCP3* gene
- Heart disease and/or sudden death (especially at a young age – less than 50 years old)

In the setting of a known family history of a *MYBCP3* gene mutation, we recommend testing for at-risk relatives by the age of 10-12 years old since this is the age at which cardiac screenings (echocardiogram, EKG) would begin for individuals who have a positive genetic test.

If you have any questions about HCM4, please contact the staff at The Community Health Clinic at 260-593-0108.

AUTOSOMAL DOMINANT INHERITANCE



CLINIC NEWS & UPDATES

WELCOME

Alondra A. Belmares
Clinical Research Coordinator

Alondra joined The CHC in January 2024 as a Clinical Research Coordinator. Alondra has experience in family medicine, OBGYN, and the ER as a medical assistant and patient care tech.

She is a very proud mom of two little boys. In her spare time, she enjoys spending quality time with her family, reading books, and watching sport events with her husband and is currently working to obtain her bachelor's in healthcare and business administration through Western Governors University.

She is excited to be part of the CHC team and looks forward to getting to know the patients as well as expanding her knowledge on the research side.

Jaime Cunningham
Finance Manager

Jaime began working at the CHC in March 2024 as the Finance Manager. She will be responsible for the day-to-day accounting and financial management as well as human resources at all CHC, Inc. facilities.

Prior to taking this new role at CHC, Jaime spent almost fourteen years at a local independent pharmacy, gaining experience in finance, business management, and human resources. She grew up locally and graduated from West Noble High School in 2006. She then graduated with distinction from Indiana University in 2010, earning a Bachelor of Arts in History with minors in Business Management and Anthropology.

Jaime and her husband, Lyle, reside in Noble County and are kept busy raising their two sons and working on the family farm. Jaime enjoys reading novels and creating delicious treats in the kitchen during her free time.

Nicole Drass, CPT
Medical Assistant

Nicole is a licensed phlebotomist with 20 years of experience. She is from Ohio and attended Owens Community College. Nicole moved here to Indiana in October of 2021, as her husband is from here, and is excited to be a part of the CHC and learn about a new part of the medical world.

In her free time, she enjoys spending time with her daughter, who is a trauma ER nurse, as well as traveling back to Ohio where she likes to camp and fish at Lake Erie all year round.

Erin Kline, OTD, OTR/L
Occupational Therapist

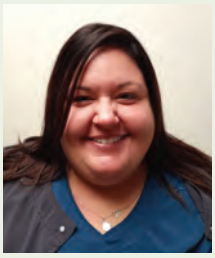
Erin is a licensed occupational therapist at the Community Health Clinic. Erin started working with the Community Health Clinic in the winter/spring of 2023 completing her capstone project to develop a pediatric therapy program. Erin officially joined CHC as an occupational therapist in June 2023 after graduating with her doctorate in occupational therapy from Huntington University.

In 2020, Erin graduated from Huntington University with her bachelor's degree as an occupational therapy assistant and has worked at Van Wert Health and Lutheran Life Villages. Erin is from northwest Ohio and moved to Kendallville after she married her husband in 2021. Outside of work, Erin enjoys spending time with her family, traveling to new places, and playing sports like volleyball or basketball.

Grace Lewis, BS
Genetic Counseling Assistant

Grace received her undergraduate degree in Genetics, Cellular, and Molecular Biology from Purdue University Fort Wayne. Before coming to the Community Health Clinic, she was a genetic counseling intern at Riley Children's Hospital's department of developmental genetics. Outside of work she likes to stay active, be outside, and spend time with friends, family, and pets.

Brandi Randall, CMA
Medical Assistant



Brandi grew up in Rome City but currently resides in Kendallville with her 8-year-old daughter, Bryn.

She graduated college from Brown Mackie with an Associate's Degree in Nursing. She has previously only worked in long-term care, but is looking forward to this new adventure here at the Community Health Clinic. She is excited for all of the new things she will learn as well as the new people she will be able to meet.

STAFF RECRUITMENT

Health Clinic Positions

METABOLIC DIETITIAN

The CHC is seeking a full-time Metabolic Dietitian to perform a variety of duties related to nutritional therapy for patients. Visit www.indianachc.org to learn more.

Interested candidates should send his/her CV to Rhonda Anderson, Director of Patient Services at randerson@indianachc.org.

GENETIC COUNSELOR

The CHC is seeking a Genetic Counselor to assist patients and families in understanding and adapting to known or potential genetic disorders. Visit www.indianachc.org to learn more.

Interested candidates should send his/her CV to Rhonda Anderson, Director of Patient Services at randerson@indianachc.org.

PHYSICIAN GENETICIST

The CHC is seeking a Physician Geneticist interested in treating children and adults with metabolic and genetic disorders.

Interested candidates should send his/her CV to Jared Beasley at jbeasley@indianachc.org.

DENTAL CLINIC POSITIONS

DENTIST

The CDC is seeking a Full or Part-time Dentist interested in treating children and adults in an underserved rural community. This position offers the unique opportunity to work at a well-established, non-profit dental clinic with an experienced team who are passionate about serving their community.

Interested candidates should send his/her CV to Dr. Brian Blough at bblough@thecommunitydentalclinic.org.

DENTAL HYGIENIST

The CDC is seeking an experienced Dental Hygienist to join our team. This position includes full time pay and benefits with a four-day work week (Monday-Thursday).

Interested candidates should send his/her CV to Natalie Covell at ncovell@thecommunitydentalclinic.org.

DENTAL CLINIC ASSISTANT

Excellent opportunity for a new career as a full-time, four-day work week as a Dental Clinic Assistant! Prior experience is not required; we are willing to train and invest in the right candidate for our thriving, patient-centered practice.

Interested candidates should send his/her CV to Natalie Covell at ncovell@thecommunitydentalclinic.org.

OUTREACH CLINICS

In addition to seeing patients in our main facility in Shipshewana, CHC offers periodic outreach clinics in outlying communities in Indiana including Berne & Paoli, and also in Clare, Michigan. The next scheduled outreach clinics in Berne are June 21st and July 12th. For other locations & dates, appointment availability, and additional information including whether an outreach clinic is appropriate for you, please contact us at 260-593-0108.

EDUCATION EVENTS

The CHC staff encourages attendance at genetics education events for interested community members. We have five events scheduled in June and July. Contact us at 260-593-0108 for additional information and registration:

Low-Protein Foods Grocery Shopping
CHC in Shipshewana, June 1st at 9:30 AM

General Education about CHC
Arthur, Illinois, June 13th at 6:30 PM

VLCADD & LGMD Education
Berne, Indiana, June 21st at 6:30 PM

The Importance of Genetic Research
CHC in Shipshewana, June 25th at 6:00 PM

Education for Midwives
CHC in Shipshewana, July 18th at 8:00 AM

GENETIC CAUSES FOR SEIZURES (EPILEPSY) *Continued from page 1*

information about the chance for other family members to have epilepsy (i.e. if the genetic disorder is inherited or if it occurred brand new or de novo in the child).

Some genetic disorders that cause seizures also come with other health problems such as difficulty walking (ataxia), low muscle tone, and/or intellectual disability.

Certain genetic seizure disorders are more severe than others, so sometimes seizures cannot be controlled no matter how many medications are taken. Examples of this are SCN8A-related seizure disorder, CLN6 or Batten Disease, and lethal neonatal rigidity and multifocal seizure syndrome (RMFSL) caused by BRAT1 gene mutations. In these instances, palliative care is more appropriate so a patient can have as much time as possible with his/her family and remain comfortable. Genetic testing and finding a diagnosis can help determine if this is the correct path to take. Testing can also help guide families to the best resources for care.

The Community Health Clinic is staffed with providers that can help the community in understanding their seizure disorders better. We want to make it easy for your family to navigate the health care system. We can provide a medical home to help with coordinating and facilitating your care with outside providers and to be an advocate for you and your child.

VOLUNTEERS NEEDED FOR RESEARCH STUDY

The Community Health Clinic

We invite you and other adults in your family to participate in a research study conducted by Dr. Zineb Ammous from The Community Health Clinic (CHC). This research study is called "Characterizing Genetic Diversity in Plain Populations" or "GDPP" or "Plain Wellness Study" for short. Dr. Ammous and other researchers around the United States are trying to identify gene changes in the Plain population to learn how these changes may affect health. This study may help doctors care for your community better by learning how differences in genes affect the body, which may aid in the diagnosis and treatment of certain medical conditions.

WHO CAN PARTICIPATE?

You may be in this study if you are 18 years of age or older **AND** you are of Plain (Anabaptist) ancestry, including Old Order Amish and Mennonite.

WHAT WILL HAPPEN IN THE STUDY?

If you choose to participate, you will engage in one approximately 1-hour long study visit at the CHC or other location. You will answer questions about your health, medication, and family health history. You will have measurements taken (blood pressure, height, weight, etc.) and blood drawn for routine clinical blood tests and genetic testing. The CHC will provide a letter with results and follow-up information.

HOW DO I GET MORE INFORMATION ABOUT THIS STUDY?

Please contact the CHC Research Department at research@indianachc.org, 260-593-0108 (ask for a Research Coordinator), or 730 E North St, PO Box 329, Shipshewana, IN 46565.

SPECIAL THANKS TO OUR BUILDING CAMPAIGN CONTRIBUTORS

We are most grateful for and humbled by the many hands that came together contributing the funds, labor, materials, and expertise that helped make this $4.06 million project possible. With thoughtful planning and your generous support, we were fortunate to move into the first clinic building of our own, on time, and on budget.

Now in our 11th year of service, and mostly settled in the new facility, we have already been able to meaningfully grow our clinical services, education programs, and patient-centered research initiatives. None of this work is done alone. Without the collaboration of our patient families, the communities we serve, and a growing number of medical and research partners, this work would not be possible.

Thank you again to the many friends who share our mission & vision and work together with us to advance medical knowledge and improve the quality of life for all those affected by rare disorders.

The staff of The Community Health Clinic at the Fall 2023 Openhouse

$100,000 & Above
- Anonymous (4)
- Community Foundation of Elkhart County

$10,000 - $99,999
- Anonymous (12)
- Bontrager Family Foundation
- Farmers State Bank
- Lagrange County Community Foundation
- Rob & Stephanie Myers

$1,000 - $9,999
- Anonymous (32)
- Anabaptist Foundation
- Blake & Karla Andres
- Jared & Karla Beasley
- Bright Star Realty & Auctions LLC
- Donald R. & Janet W. Daut
- Graber Steel & Fabrication LLC
- The Harvest to Share, Inc.

Up to $999
- Anonymous (65)
- Garrett Bergman, MD
- Robert & Lea Anne Einterz
- Brandon Esh
- Phillip & Thelma Martin
- Razor Sharp Tooling

$231,000 IN KIND DONATIONS
Materials, Labor, & Furnishings

2024 COMMUNITY FUNDRAISING

Each year, community benefits and church donations support approximately one-third of The Community Health Clinic's annual operating budget. These contributions help us provide high-quality, personalized medical care at significantly reduced costs for families affected by complex medical conditions.

Many thanks to the hundreds of volunteers who come together to plan and hold the auctions and dinners. CHC's Contact Couples, benefit planning committees, and the auction boards work throughout the year to bring thousands of community members together to help support our mission.

Thank you to all who have participated in this year's fundraisers so far. On March 1st, over 1,300 *Haystack Suppers* were shared during the annual gathering at Harrison Christian School in Goshen, and we were blessed again with large crowds for the *Tri-County Auction* on April 19th in Topeka. We're most grateful for the opportunities to share stories of the work we do together; your generosity makes a big difference in the lives of those we serve.

Nappanee Benefit Auction

Join us on **Friday, July 19, 2024**, beginning at **4:30 PM**

CLAYWOOD EVENT CENTER
13920 N 1100 W, NAPPANEE, IN 46550

13th Annual Dutch Dinner

Save the date: **November 9, 2024**

SAMMLUNG PLATZ
758 N TOMAHAWK TRAIL, NAPPANEE, IN 46550

The last several years, the annual Dutch Dinner event has sold out. If you would like to reserve your 2024 Dutch Dinner sponsorship early, or have any questions about any of our benefit events, please contact us by phone, 216-593-0108 or email, info@indianachc.org.

The Community Health Clinic

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Shipshewana, IN 46565

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SECOND ANNUAL WALK FOR RARE, RUN FOR HOPE 5K

SAVE THE DATE

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This board governs The Community Health Clinic and the Community Dental Clinic.

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