



# The Community Health Clinic

Vol. 6, Issue 1

A Newsletter for the CHC

Winter 2021

## From the Executive Director



**Jared Beasley, MBA, RN**  
Executive Director

At the Community Health Clinic, we've had much to be thankful for in 2020. We continue to be able to provide much needed care to our patients and have found new ways to make ourselves accessible despite limitations from the pandemic. Our mission to provide excellent, affordable medical care consistent with the needs of our communities continues to be the focus of our work, and that focus has helped us adapt and embrace necessary changes with optimism and hope for the future. In this year of constant change, we've been so grateful for the generous support of our community. Despite having to cancel or change all of our major fundraisers, the community has continued to show support for the clinic by giving in new ways and helping to ensure we continued to thrive in 2020. We've also been grateful for collaboration with others in our industry. Thanks to those relationships, the Community Health Clinic and Community Dental Clinic continue to see new opportunities to bring care to our patients. The Plain Church Group Ministry, Indiana Hemophilia and Thrombosis Center, The Plain Community Health Consortium, local hospitals and doctors, local businesses, research partners, and universities are all examples of partnerships we've been so fortunate to continue to



have throughout this year. Partnerships like these help make the Community Health Clinic what it is today as much of our work and identity is tied to the relationships we've established and maintained. We are so thankful for this culture of support and partnership. The challenges of 2020 have shined a light on the value of community and relationships for us at the clinic. As we close the year, my hope for each of us is that we continue to overcome divisive rhetoric and hold firmly to our commitment to love our neighbors and put others before ourselves. We wish you all a happy and fulfilling 2021!

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**We recently revised our website!** Check out all the new content at [www.indianachc.org](http://www.indianachc.org)

**Interact with us on social media!**



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[www.instagram.com/communityhealthclinic](http://www.instagram.com/communityhealthclinic)

# Dietitian's Corner



Elaine Wakefield, RD,  
CD, CDE  
Registered Dietician

## Feed a Cold, Starve a Fever?

You've probably heard the old saying "Feed a cold and starve a fever." Where did that come from, and is it good advice? An article in the Smithsonian cited that this dubious statement was based on a dictionary entry from 1574 that said fasting is a great remedy for fever. As far as being good advice, medical practice has changed since 1574! Is there anything we can do with diet to improve our outcomes during cold and flu season? The answer is yes!

We can eat a variety of foods that provide sources of vitamins A, C, D and zinc to help support our immune system. While it is possible to use supplements to get large doses of these nutrients, studies show that getting them from food is a better option. There are other nutrients in the foods that play roles in building our immune systems.

The foods we eat provide nourishment to build up the physical barriers, our first line of defense against illness. Those barriers include our skin, hair and mucus membranes. They limit entry of intruding bacteria, viruses, fungi, parasites, pollen, dust, and toxic chemicals. If those walls are broken, we have the gastrointestinal tract to provide another level of defense with its immune cells and microflora.

Our remaining protector from illness is on a cellular level. Immune cells such as neutrophils, natural killer (NK) cells and macrophages all rush in to defend our bodies against the intruders. Other cells follow to repair and rebuild our damaged cells.

As you can imagine, these battles require energy and replenishment of our stores of basic building materials, the vitamins and minerals needed to keep the defenses strong. It wouldn't be wise to starve our body while such a battle is taking place.

Vegetable soups can be a wonderful choice for refueling our bodies. They provide needed fluids, a variety of vitamins and minerals and are easy to prepare and eat. Ideally the soups should be made from fresh or frozen vegetables and not from a can of highly processed soup that has been sitting on a shelf for ages! In a pinch, even a can of condensed soup can be acceptable. Add a few fresh or frozen vegetables to it to enrich the nutrients.

*The foods we eat provide nourishment to build up the physical barriers, our first line of defense against illness. Those barriers include our skin, hair and mucus membranes.*

Studies have shown that micronutrient deficiencies can lead to breakdowns in our immune systems and make us at increased risk for infections. Don't wait until you feel the first symptoms of a cold or flu. Start eating more fruits and vegetables today to build your immune status and lower your risk for illness during cold and flu season.

# Newborn Screening Updates



**Jody Werker, RN**  
Newborn Screening Coordinator

Indiana newborn screening has again expanded. On March 25th 2019 Senate Bill 41 was signed into law. This added three new conditions to the panel including Krabbe disease, Pompe disease, and Hurler Syndrome which is also known as MPS-1. Screening for these disorders officially began on July 1, 2020.

Krabbe disease, Pompe disease, and Hurler Syndrome are three of about 50 conditions known as lysosomal storage disorders (LSDs). LSDs are inherited metabolic diseases that happen due to an accumulation of toxins or waste products in the body's cells. As indicated by the name LSDs are a problem in a particular part of the cell called the lysosome. Lysosomes are small organelles found in every cell in the body. They contain enzymes or acids that break down proteins, carbs, and fats into smaller molecules the body uses for various functions such as building muscle, making energy, etc. Lysosomes also break down excess or worn out cell parts and help destroy them. Additionally, lysosomes ingest and destroy bacteria and viruses.

Each LSD is related to a specific enzyme deficiency. This happens when the body is missing the correct instructions in the gene that makes a particular enzyme that aids in getting rid of the waste products or breaking down larger

molecules. As the waste products or other molecules accumulate they may affect different parts of the body such as the skeleton, brain, skin, heart, liver, muscles, spleen, and central nervous system. Symptoms may start in infancy, develop during childhood, or may not present until adulthood. Symptoms and severity vary even within a particular disorder and can include intellectual disability, delays in physical development, seizures, facial or other bone deformities, joint stiffness & pain, breathing problems, enlarged heart, problems with vision and hearing, anemia, nosebleeds, easy bruising, abdominal swelling due to an enlarged liver or spleen, or behavior problems such as aggression or hyperactivity.

Many LSDs do not yet have a treatment. However there are now therapies for several LSDs that greatly improve the quality of life for those affected. Screening for these inherited conditions within 24 to 48 hours after birth allows for early disease detection and intervention, preventing negative outcomes such as neurological issues, respiratory failure, heart failure, and even death. Without screening, these disorders would be undetected until after onset of symptoms.






**Sharon Chupp, RN, CEN**  
Clinical Supervisor/Newborn Screening Coordinator

## NEWBORN SCREENING

*The Three Parts to Newborn Screening*

*Did you know?*  
All babies in the United States receive newborn screening.

-  **Blood test or heel stick**  
A small blood sample is taken from your baby's heel and placed on a newborn screening card. This card is mailed to a state laboratory for analysis.
-  **Hearing screen**  
One of two tests may be used to screen for hearing loss in your baby. Both tests are simple and safe and can be done while your baby is asleep.
-  **Pulse oximetry**  
Pulse oximetry is a test that measures the amount of oxygen in your baby's blood and can detect some heart problems called Critical Congenital Heart Disease (CCHD).




Photo source: [www.babysfirsttest.org](http://www.babysfirsttest.org)

# Providing Telehealth During the COVID-19 Pandemic



Nicole Bertsch, MS, CGC  
Genetic Counselor

When the COVID-19 pandemic hit in March, we had to re-evaluate our model of care at the CHC. Specifically, we had to think through how we could safely see patients while still remaining true to our mission of providing excellent, affordable medical care. This is when telehealth entered the picture.

Telehealth is a model of delivering healthcare using digital information and communication devices such as phones and computers. This model means that patients and healthcare providers are not in the same room together face to face. This then allows patients and healthcare providers to limit their exposure to infection. In addition, telehealth

*We have found that many of our services can be delivered as effectively via telehealth as they can in person. Even genetic testing can often be coordinated without a patient coming into the clinic.*

can often be more convenient: patients can use technology from their homes instead of traveling to a clinic, and providers can sometimes see more patients in a day via telehealth than they can in person.

The CHC had not routinely used telehealth for service delivery prior to the pandemic, so it has been an adventure! We have a few different telehealth models now at the CHC:

- A patient comes to the CHC and has a video visit with a provider over the computer via a platform called WebEx. Since this platform has visual and audio capabilities, the provider can see the patient and assess some physical features/findings. The provider can also share educational resources over the platform and view them together with the patient.
- A patient uses the WebEx platform from his or her home to meet with a provider.



- A patient calls the CHC at a specified, agreed upon time and is connected with a provider for a phone appointment. This works great for patients who do not have the ability to use WebEx in their home.

Since March 2020, the CHC has provided over 300 telehealth visits.

The largest limitation of telehealth is a constrained ability to perform physical exams. Therefore, the CHC providers indicate to our scheduler whether an in-person or telehealth visit is most appropriate for a patient, and this is then communicated to the patient when the appointment is scheduled. We have found that many of our services can be delivered as effectively via telehealth as they can in person. Even genetic testing can often be coordinated without a patient coming into the clinic. Instead, a saliva sample collection kit can be shipped to the patient's home. We are also able to bill for telehealth visits the same way we bill for in clinic visits, so this model appears to be financially sustainable.

While 2020 has been challenging in many ways, it has forced us to grow as a team and reexamine how we deliver medical genetics care. We are excited by the prospects of telehealth to expand our services to more patients. We are also thankful for our patients who quickly adapted to a new model of care.

# Memories saturate my heart and the story of you spills from my eyes

2020 was a difficult year to say the least. It was especially difficult for those who lost loved ones, and more difficult still for those who lost a child. Losing a child is arguably the most challenging loss a person can face in life. Six of our beautiful CHC children have passed in 2020. To the families of these six children:



**Zineb Ammous, MD,**  
FACMG (Dr. Z)  
Clinical Geneticist and  
Medical Director, The CHC

We are here for you.  
If you need anything, just ask.  
Your child was more than just a patient.  
You are always in our thoughts and prayers.  
Your precious child meant so much, and will be forever in our hearts.  
I personally cannot stop thinking about you and your family.  
Your children were my children, but in a different way  
I still hear their giggles and see their happy faces  
I remember the challenging days we've had together  
And I know they are running freely in a much better place

As a mother who has experienced loss, I can tell you this: Loss cannot be described in words. Loss is a lifelong experience and a rollercoaster of emotions. There is no right way to grieve; there is only your way to grieve, and no two people grieve in the same way. The truth is, grieving and acceptance are not one-time occurrences. It is okay to grieve forever. It is okay to cry even when it seems like you should not. It is okay to accept your loss some days and not others. With time, we heal from the losses we have suffered, but we will never be the same.

## Immortality

“Do not stand at my grave and weep  
I am not there, I do not sleep.  
I am a thousand winds that blow,  
I am the diamond glint on the snow.  
I am the sunlight on ripened grain,  
I am the gentle autumn rain.  
When you wake in the morning hush  
I am the swift, uplifting rush  
Of quiet birds in circling flight,  
I am the soft starlight at night,  
Do not stand at my grave and weep  
I am not there – I do not sleep.”



*Clare Harner Lyon*

# Clinic Happenings



Virtual staff meetings became the norm in 2020



Dr. Z performs an EKG



Dr. Z, Nicole, and Lori at an outreach clinic in Berne



Setting up for an outreach clinic in Clare, Michigan



Debbie setting up a telehealth visit in Paoli, IN

# Community Dental Clinic Update

What a year 2020 has been! Who could have predicted that we would be affected by a world pandemic? While COVID-19 (Coronavirus) has led to a time of uncertainty, it has also been a time of reflection and growth. At Community Dental Clinic, we have experienced what feels like years of growth and change over the past several months. We have evaluated different policies and procedures and spent a vast amount of time learning how we can improve upon the patient experience, while keeping everyone as safe as possible during the pandemic. That means we have had to make changes. Below you will see how this may affect our patients and families.

- **We now ask for a 48 hour confirmation call.** This allows us to screen patients and visitors for COVID-19 symptoms prior to arrival. That keeps our patients and staff safe and continues to allow us to provide services. It also helps keep our community safe by stopping the spread of a virus that may have a catastrophic effect on certain individuals. Since we were shut down for several weeks this past spring, we have many patients waiting to be seen for treatment. When a confirmation call doesn't occur, we fill the spot with another patient who has been waiting for a visit. That helps us continue to see patients in a timely manner. Lily, Angie and Alexis are the busy bees working up front that spend a lot of time screening our patients, making phone calls, coordinating care and so much more!
- **We ask that patients arrive 15 minutes prior to the scheduled appointment time.** This allows us to perform an in-person screening, take temperatures and update necessary paperwork. As recommended by the American Dental Association (ADA), we have our patients do a pre-procedural rinse of 1% hydrogen peroxide, when age-appropriate, that helps kill bacteria and viruses.
- **The Centers for Disease Control and Prevention (CDC) recommends anyone age 2 and over should wear a mask in public settings.** Dental procedures present an increased risk for spreading the virus because particles can become aerosolized (airborne), making it vitally important for both those we serve and our team to implement additional safeguards, like masks. We serve a population with complex medical backgrounds and those of advanced age; we want to do all we can to protect our patients and our team, so that we can continue to serve our community's dental needs.
- **We are limiting the number of people in the office.** One adult may accompany a child or an adult needing extra assistance. We kindly ask that other members of the family are not brought along, unless you are a nursing mother. By limiting the number of individuals in the office, we can better maintain proper physical distancing and minimize the risk of exposures.
- **We continue to apply infection control practices that have always been in place in our office.** In addition, we are taking extra measures to ensure a clean and safe environment for both our patients and clinicians. In order to do that, we have allowed extra time between patients. You will also notice extra barriers to avoid cross contamination. If you see Karla in our office, please thank her. She is on the clinical team and has high standards when it comes to infection control, which is exactly how it should be! She never stops moving and works to keep the office flowing!
- **Our dental team will look a little different too!** We now wear gowns in the operatory that are changed between every patient to help stop the spread of COVID-19, along with protecting our clinicians. Some members of the clinical team will wear face shields and N95 masks/respirators. Dr. Sarah, Cheri, Amanda, Erika, Whitney and Brittany are the hard-working members on the clinical team that endure warm temperatures thanks to all the extra layers (gown) and wearing a respirator for hours on end. It has been overwhelming at times, but they continue to tirelessly provide the care and services that our patients need.

Please know that our ultimate goal is to keep our patients safe and our team safe, not make life more challenging than it already may be. We thank you for your continued commitment and support as we work through this together! Blessings and good health to you all!

# Welcome to our New Team Members!



On November 30th, we welcomed **Blake Andres** to the Community Health Clinic, Inc. as the Director of Development and Planning! Blake will provide leadership for both the health and dental clinics in the areas of development, fundraising, marketing and planning. Blake will work remotely from his home in Chesterland, Ohio with regular on site visits to Topeka as needed. Blake has twenty-five years of leadership experience furthering initiatives that leverage science, technology and medicine for the betterment of community. Before joining

the Community Health Clinic, Inc. Blake served for 8 years as Executive Director of DDC Clinic for Special Needs Children in the Geauga Amish settlement of northeast Ohio. DDC Clinic's mission, like that of CHC's, is to improve the quality of life for families affected by rare genetic disorders. Prior to his role at DDC Clinic, Blake was Vice President, Strategic Initiatives at the Great Lakes Science Center in Cleveland and also served in leadership roles at the Arizona Science Center in Phoenix. Blake earned a bachelor's degree in zoology from Arizona State University and a master's in science education from Clarion University of Pennsylvania. In 2011, he completed a year-long fellowship in leadership development with the Noyce Leadership Institute, an experience he credits for defining his career focus. Blake and his wife Karla, an occupational therapist, have two children, Bryant and Claire, both in college. In his free time, Blake enjoys gardening, cooking, hiking and canoeing.

**Alexis Rockey** joined the Community Dental Clinic as a receptionist. Here is a little bit about Alexis:



I was born and raised in Northern Indiana, mainly in Ligonier. I enjoy the small town living and nature. Nature and enjoying its peace has always been a huge part of

who I am. I'm a new mom, to a son born in January of 2020. He is a huge blessing and learning experience all in one. My family is what means most and keeps me going most days. Dental has always been an interest of mine, starting with braces as a young teen. This really opened me up to the field and made me want to learn more. I attended Ivy Tech for the dental assisting program and graduated in 2016 with an Associates of Applied Science in Dental Assisting. The most rewarding part of working in dental is being able to help give people their smiles back.

## Research Updates



**Rebecca Evans, MS, CGC**  
Genetic Counselor &  
Research Coordinator

During 2020, the CHC ramped up its research efforts. Currently, we are helping connect or enroll patients in two studies. The Replace Registry, a multi-center study with Travers Therapeutics, is researching long-term safety and outcomes for patients with bile acid synthesis disorders, like Zellweger spectrum disorder, who are treated with Cholbam/Kolbam. The other study, conducted in collaboration with the Clinic for Special Children and Biogen, examines how a marker in the body may indicate disease severity for SMA in pregnant women at risk to have a baby with SMA and in individuals affected with SMA.

Unfortunately, COVID-19 has not allowed us to start many of our upcoming studies quite yet, but be on the lookout for studies related to Amish MYBPC3-related hypertrophic cardiomyopathy, propionic acidemia, and Zellweger spectrum disorder, as well as a general study looking at genetic diversity in the Plain population at large. We also anticipate involvement with studies related to phenylketonuria (PKU)/phenylalanine hydroxylase (PAH) deficiency and limb girdle muscular dystrophy. If you have questions about any of our research projects, please contact Rebecca Evans, Research Coordinator at the CHC, at 260-593-0108 ext. 114.



# Student Testimonials

Despite the pandemic, over the last year the CHC hosted several students for clinical rotations and other learning experiences. Here are a few of their reflections on their time with us:

My name is Katie Mascia, and I'm in my fourth year of residency training in Medical Genetics and Pediatrics. I had the amazing opportunity to work with Dr. Ammous and all the staff at the CHC during the month of November. I was even able to join Dr. Z at her outreach clinic in Berne and experience working with many different communities within the Plain population in Indiana. I learned so much from my experience at the CHC, and I was able to meet fascinating patients and their families! It is so impressive how the CHC is able to make the highest quality genetics care accessible to the Plain population. I truly appreciate the CHC staff for helping me to learn from this special population of patients even in the height of the COVID-19 pandemic.

**-Katie Mascia, MD**



I am a non-traditional student of 67 years of age, studying for my Family Nurse Practitioner degree. My goal is to open a much needed clinic for the Plain community in rural northwestern Pennsylvania. My time in Topeka for my clinical rotation has been utterly spectacular. The Community Health Clinic provides the utmost care in treating their patients. The knowledge I have gained concerning the rare and unusual genetic disorders has been tremendous. Dr. Z, Jennifer Saggors, PA, and the staff are such a well-oiled machine when working with each of their families. I thank them from the bottom of my heart for the opportunities they have given me in my journey.

**-Janeen Beard**



I am truly grateful for this experience and appreciate the time, generosity, and guidance that I have received from my preceptor Elaine and the other staff at The Community Health Clinic. I have learned a lot during my four-week rotation about the unique work done

at the clinic. I have also witnessed the communication and teamwork that is responsible for the outstanding care that is provided, even amidst a global pandemic. I will carry the insight and knowledge that I have gained with me into future rotations and into my practice as a registered dietitian.

**-Miranda Knutson**



My experience at the CHC has been nothing less than amazing. Though it was short in duration, I was able to learn and experience so much during my time at the clinic from my preceptor Elaine, the other staff, and the patients. As I continue on my academic journey and enter the professional field of dietetics, I will always remember and forever be grateful for this opportunity to gain experience in metabolics at the CHC.

**-Peyton Paul**

# A special thanks to the sponsors of our 2020 Dutch Dinner!

We are humbled by the generous financial donations we received even though we could not host our traditional, in-person fundraiser! In lieu of our typical Dutch Dinner, our staff, community members, patients and industry partners put together a series of “mini talks” on topics ranging from the future of the CHC to dietetic tips to genetic inheritance patterns. These videos are premiering on our social media platforms (Facebook and Instagram) and being posted on our website. The mini talks will be made available in a written format in early 2021.

Stay tuned!

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# The Community Health Clinic

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## Upcoming Events:

Due to the ongoing pandemic, most of our events are on hold or have been postponed to late 2021. Stay tuned!

**Governed by a community-based board of directors, the CHC strives to ensure that the values of the community are reflected in the services, growth, and direction of the organization.**

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**Jared Beasley**, Director

**Merlin Weaver**, Director

**Rob Myers**, Director

### **Staff:**

**Zineb Ammous**, MD, FACMG  
Clinical Geneticist and Medical Director

**Jared Beasley**, MBA, RN  
Executive Director

**Deborah Jurgielewicz**, ABA, AAS, CMBC  
Operations Director

**Blake Andres**  
Director of Development and Planning

**Jennifer Saggars**, MMS, PA-C  
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**Elaine Wakefield**, RD, CD, CDE  
Registered Dietician

**Nicole Bertsch**, MS, CGC  
Genetic Counselor

**Rebecca Evans**, MS, CGC  
Genetic Counselor & Research Coordinator

**Sharon Chupp**, RN, CEN  
Clinical Supervisor/Newborn Screening Coordinator

**Lori Arnold**, RN  
Clinical Nurse

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Newborn Screening Coordinator

**Teresa Moser**, RN  
Clinical Nurse

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