



YOU ARE NOT ALONE

Dr. Zineb Ammous, Medical Director

The diagnosis of a child with a rare genetic disorder has a profound impact on the whole family. No parent wants his or her child to be disabled or sick. When the disorder causes serious health problems, disability, or an early death, parents find themselves on the uncharted and often harrowing journey of becoming caregivers for life. This journey can be a roller coaster of emotions; shock, denial, grief, guilt, anger, and confusion. Such emotions can be experienced at any point throughout this journey, and in no specific order. This is normal and acceptable; no parent of a child with special health care needs should feel ashamed or guilty about these emotions.

With time, many parents find the strength within themselves to adjust to their “new normal,” learn how to become caregivers, establish a routine, and regain stability in life. However, it is not that simple. Being the parent of a child with serious health care needs requires a lot of resilience. As a caregiver, you must continually adapt to stress and learn to manage challenges that confront you unexpectedly throughout the journey. This often leads to significant personal growth over a short period but can also result in exhaustion and burnout over time, no matter how much you love and care about your child.

So why is caregiving so exhausting?

1. Interacting with your child with a disability or special health care needs requires **extreme patience**. Emotions run high for everyone involved, and everything seems to move at a slower pace. Daily appreciation of the smallest things helps increase your patience, empathy, and compassion that will allow you to be an effective caregiver. As Joyce Meyer puts it, “*Patience is not simply the ability to wait—it’s how we behave while*

we’re waiting.” It is also very important to remember to laugh. Caregiving does not have to be so tense and serious.

2. One thing all caregivers have in common is the **large amount of time** they devote to the task. On average, a caregiver will spend more than 57 hours a week caring for a family member with disabilities. That’s more than 8 hours a day, on top of all their other duties and responsibilities. It is easy to see why so many caregivers can feel overwhelmed.
3. Many caregivers want to do it all. They feel responsible for their disabled child and feel like they have failed if they **ask for help and support**. There is no immediate “cost” for your time or the emotional and physical stress you experience while taking care of your disabled child but, in the long run, protecting your mental health is key. In addition, using help and resources allows you to spend time with your child that is enjoyable and memorable.
4. **Non-caregivers can be judgmental.** Interacting with people who do not understand your situation can be very frustrating and exhausting. It often leads to avoidance of social interactions and anxiety surrounding the many assumptions and questions you encounter when you are out and about. It is very important to accept that there is no way for those who do not live in your shoes every day to understand what it is like. When days are very difficult and social interactions are emotionally taxing, it is okay to avoid people and keep to yourself until you are ready. There is no right or wrong way of doing this. Also,



Dr. Ammous and her son Ibrahim.

it is helpful to make friends who went through similar life experiences so you can share and learn from one another.

5. As caregivers, we often **forget to push the pause button**. Creating balance is a challenge even for the most organized caregiver. Most caregivers do not make time for themselves to recharge. Sleep is usually the last thing on the list; this leads to sleep deprivation and several related health issues. Caregiver mental health problems can be seen as a sign of weakness and failure when in fact they are a sign of exhaustion and burnout. *Hit that pause button!*

In summary, taking care of a child with special health care needs is physically and emotionally demanding. Seek help, use the available resources, and make time for yourself amid the chaos. Pay attention to your mental health. Staying healthy, both physically and emotionally, is the foundation to taking care of others.

NEW CLINIC BUILDING CONSTRUCTION UPDATE



Progress on the new facility is moving forward according to schedule. After the groundbreaking in May, foundation work commenced in June and framing of the two-story building began in July. As of November 1, the shell of the building is nearly complete, and work has begun on the mechanical and electrical systems. Our goal is to have the facility completed in the summer of 2023 and be moved in by September — in time for The Community Health Clinic’s tenth anniversary.

The main floor of the new building features an increased number of patient care rooms to meet the needs of a growing community. These rooms will be significantly larger, providing increased comfort for patient families with complex medical needs. The building will support and grow existing partnerships and new collaborations providing expanded services including sub-specialty clinics, such as hemophilia, neurology, cardiology, and others.

Our new clinic will have dedicated rooms for genetic counseling, dietary services for those with metabolic disorders, and spaces to host an increased number of patient-centered research studies. Our research focus is twofold: building enhanced understanding of the rare genetic disorders that affect our patient families, and leveraging that understanding to help develop new therapies and treatments. The facility will also have several meeting rooms to accommodate both small and larger groups. The walkout basement features a Community Room to host education events and disease-specific family gatherings. To date, we have not had those capabilities, having to borrow, or rent space to bring families together.

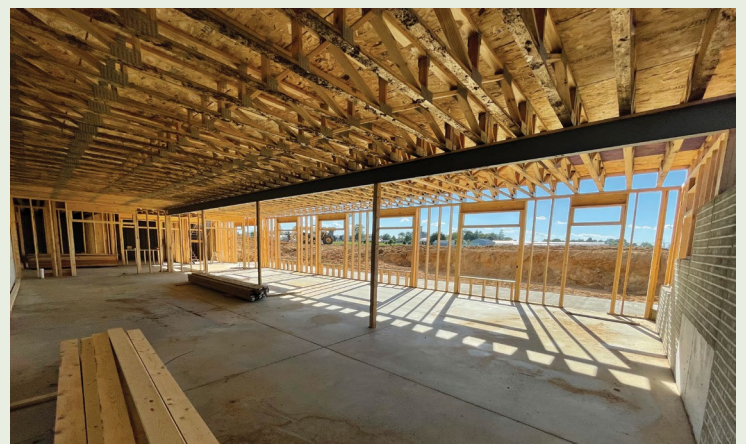
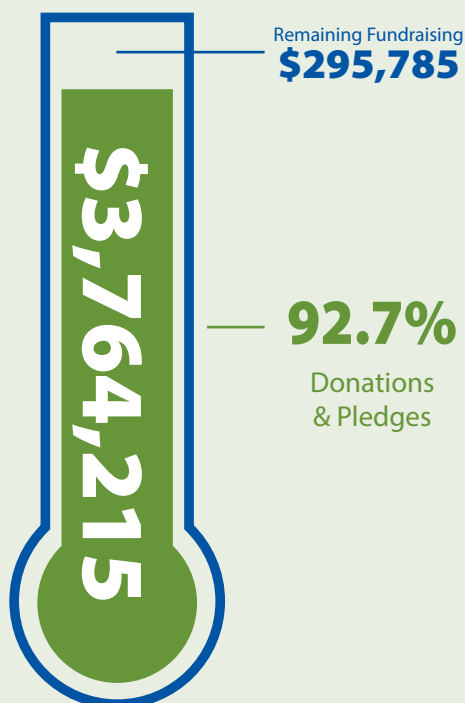
We are grateful for our community’s generosity and have had diverse support from businesses, foundations, and a growing number of individuals. Since launching the building campaign just one year ago, we

have raised 92.7% of our \$4.06 million goal. These donated building funds supported the purchase of ten acres of land and the construction underway of the 15,000 square-foot clinic. All the funds raised for the building were restricted specifically for this purpose. With just \$295,785 yet to raise, our goal remains to complete the funding prior to move-in. Our generous challenge match remains, every dollar donated leverages a matching dollar in return from an anonymous donor.

Please visit our website for additional information about the campaign, contributors, and updates on the building progress. If you have any questions about the campaign, or would like to help in some way, please contact Blake Andres, Director of Development and Planning at bandres@indianachc.org or 260-593-0108.

COMMUNITY HEALTH CLINIC BUILDING CAMPAIGN

PROJECT GOAL: **\$4.06 MILLION**



The facility will have several meeting rooms to accommodate both small and larger groups.

NEWBORN SCREENING: FROM BARRIERS TO EXCELLENCE IN CARE

The Community Health Clinic (CHC) developed the DAS KIND program in 2013. DAS KIND, means the child, but is also an acronym for Knowledge and Intervention through Newborn Diagnosis. Why is that important for a local clinic to provide this kind of service? Prior to 2013, all newborns who were detected with having a metabolic condition through the Indiana newborn screening program were sent to one metabolic center in Indianapolis. That means that any newborn that needed specialized metabolic follow-up care had to go to Indianapolis to receive care. As one can imagine, this presents barriers to care for some due to transportation, cost, and access difficulties. Together, Dr. Z and CHC staff developed this program to provide local genetic and metabolic care for all newborns, addressing barriers to care and improving outcomes in the community. In 2013, The CHC applied for and was awarded a contract with the Indiana State Newborn Screening program to provide follow-up care for metabolic conditions in 11 counties in NE Indiana. For 9 years the clinic has grown this program and now provides follow up for metabolic conditions and other rare genetic conditions such as SCID, SMA, and X-ALD. The clinic currently provides follow up for all of these conditions for 19 counties in Indiana. The clinic also provides follow-up care for babies who are born in Indiana but live in bordering states.

You might be asking yourself, what is newborn screening and what does it mean to do follow-up? Newborn screening is a test that every newborn in the state has performed at 24 hours of life. The newborn screening test helps screen newborns for serious, but treatable, medical conditions at birth. The conditions found through newborn screening can be present in any family, even those without a family history of them. The test is made up of three parts: blood test, pulse oximetry, and hearing screening.



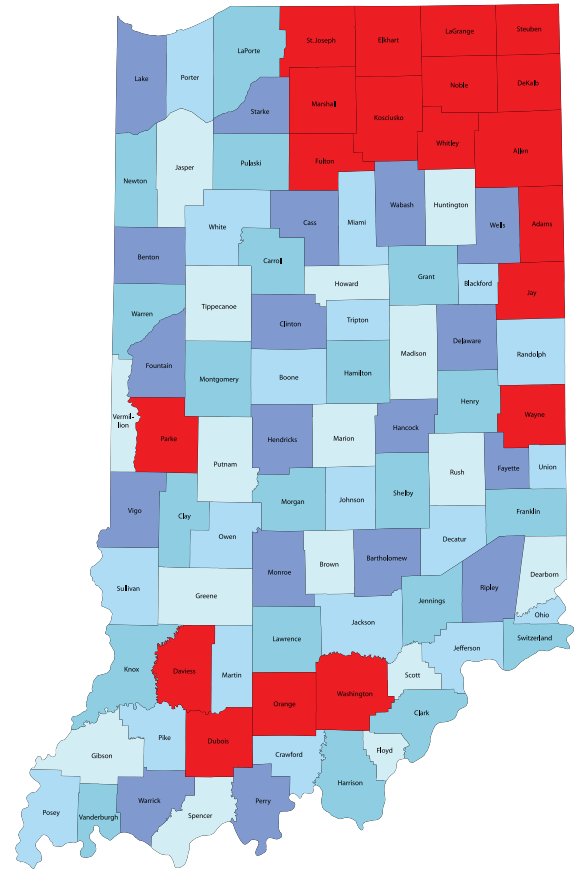
The **blood test** is commonly called the “pku test,” “heel poke,” or “heel stick.” This portion of the newborn screening takes a small sample of blood from your baby’s heel. This specimen is sent to the Indiana State Newborn Screening lab where the baby’s blood is screened for over 60 conditions. You cannot tell if your baby would have one of the conditions by just looking at the baby.



The **pulse oximetry test** measures the amount of oxygen in your baby’s blood and can detect some heart problems called Critical Congenital Heart Disease. This test is a painless test where a small sensor is placed on your baby’s skin. If the baby does not “pass” this screening, a visit to a cardiologist (heart doctor) may be necessary.



The **hearing screening** is the third part of the newborn screening. This test looks for problems with the newborn’s hearing. This test is also painless and if the baby does not “pass,” a visit to an audiologist (hearing doctor) may be necessary.



The CHC provides newborn screening and follow-up care for the blood test portion of this test. If a newborn is detected to be at risk for a condition after the specimen has been tested at the State Newborn Screening Lab, The CHC is notified. CHC Staff then take action by contacting the midwife, pediatrician, and the parents of the newborn with the abnormal screening results. The CHC staff helps provide information and discusses the next steps with families and caregivers. If the newborn is diagnosed with a metabolic condition, The CHC is able to provide local, affordable, culturally sensitive metabolic care for the newborn. CHC Staff includes a metabolic dietitian to assist with special diet needs, as well as metabolic formula. A newborn with a metabolic condition will require frequent visits to the clinic and close monitoring. Having a clinic that is local for the community has been instrumental in addressing the barriers to care and improving outcomes for patients with rare, metabolic disorders as well as SCID, SMA and X-ALD.

Since 2013, the DAS KIND program has served 429 infants referred through newborn screening. Of those 429 infants, 107 were Amish or Amish ancestry and 318 infants were not Amish. Of those 429 infants, 56 Amish infants were diagnosed with a condition and 118 non-Amish infants were diagnosed with a condition. The CHC is grateful to provide excellent, affordable genetics and metabolics care to families needing our services.

— Thank You —

After having to cancel the 2020 and 2021 fundraising events, this year we were able to hold the Tri-County and Nappanee auctions, the Haystack Dinner, and the Dutch Dinner. We're grateful for the time and efforts of all those who planned, contributed, and attended this year's events. We appreciated the opportunities to share stories of our work and for the fellowship with new and longtime friends. All four of this year's benefits were among the largest we've had! We'd like to express our appreciation to our Community Health Clinic volunteers, especially our Contact Couples and the Auction and Dinner Committees. Without your commitment, these special annual events would not be possible!

From time to time we receive thoughtful questions, asking about the use of the funds from the benefit auctions, dinners, and annual free will donations from the Amish churches. These donations help support the day-to-day operations of our clinic, allowing us to provide quality care at greatly reduced prices for patients. Keeping care affordable is important. Our goal is for the patient fees to never be a barrier to families with complex healthcare needs.

None of the contributions from the auctions, dinners and churches are used to support the construction of the new clinic building. The funding for the building is a separate but important effort and we are most thankful for all those who provided this targeted support.



April 29th Tri-County Auction, Topeka

2022 Dutch Dinner Sponsors

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Townline Furniture



July 22nd Nappanee Auction



October 3-4 Blitz Build
Shop building sold by silent bid in advance of the Tri-County auction.



November 5th Dutch Dinner, Sammlung Platz, Nappanee

IMPORTANT DATES

Closed: Monday December 26th & Friday December 30th

Haystack Benefit Supper: March 3rd, 2023 @ Christian Harrison School

Tri-County Auction: April 28th, 2023 @ Topeka Livestock Auction

Nappanee Auction: July 21st, 2023 @ Claywood Event Center

CLINIC NEWS & UPDATES

CLINIC NEWS

Welcome Annie



Annie Brinson moved to Indiana in August of 2022 from South Dakota to join The Community Health Clinic as a Clinical Research Coordinator. She received her

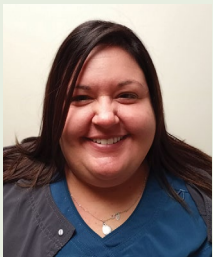
associate degree from Black Hills State University in 2014 and began her career as a Group Home Manager for Black Hills Works, a non-profit organization that provides 24-hour support for individuals with disabilities.

She went on to receive her Bachelor of Applied Biological Sciences from South Dakota School of Mines and Technology in 2021 and began working as a Clinical Research Coordinator at Avera Research Institute in Rapid City, SD.

Annie is currently pursuing her Master of Public Health degree through the University of South Dakota.

She enjoys being outside with her three children and two dogs, kayaking, running, and exploring their new home.

Welcome Brandi



Brandi joined The Community Health Clinic here in September of 2022. She originally grew up in Rome City but currently resides in Kendallville with

her eight-year-old daughter, Bryn. Brandi graduated college from Brown Mackie with an associate degree in nursing. She has previously worked in long term care, but is looking forward to this new adventure 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 ROLES

There have been a couple staff transitions in the Clinic over the past few months, one being Rhonda Anderson. Rhonda started at the Clinic as our Nurse Practitioner but has

since added Director of Patient Services to her title as well as still maintaining her role as our Nurse Practitioner. Along with Rhonda, Jessica Meyer has transitioned into a new role. Jessica started at the Clinic in January 2021 as the Medical Receptionist. Over the past several months, she has transitioned into the Development and Education Coordinator.

Staff Recruitment

HEALTH CLINIC

Physician Geneticist

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

Nurse Practitioner

The CHC is looking to add a full time Nurse Practitioner to deliver assistance and support to the Clinical Geneticist.

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

DENTAL CLINIC

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.

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 Jared Beasley at jbeasley@indianachc.org.

OUTREACH CLINICS

In addition to seeing patients in our main facility in Topeka, CHC offers periodic outreach clinics in outlying communities in Indiana including Fort Wayne, Berne, Paoli and also Clare, Michigan. The next scheduled outreach clinics include:

Fort Wayne, IN

2nd Wednesday of each month

Berne, IN

January 20th, 2023

Paoli, IN

Spring of 2023

Clare, MI

Spring of 2023

For other dates, appointment availability and additional information including whether an outreach clinic is appropriate for you, please contact us at 260-593-0108.

SPECIALTY CLINICS

Dr. Chowdhury- Cardio Clinic April 7th at the CHC. Please call Dr. Chowdhury's office at 717-925-8300 to schedule your appointment.

INTERNS



The Clinic would like to give a special thank-you to our summer intern, Kora Beasley. Here are a few words from Kora regarding her experience here with the Clinic.

I was an intern at The Community Health Clinic in the summer of 2022. Throughout my 10 weeks at the CHC, I spent time in different departments including Research Operations, Clinical Services, and Development. My position supported time for the completion of various projects, opportunity to shadow providers, and resources for substantial learning about genetics. Although I now retain a plethora of new skills and information from my experience this summer, my key takeaway from the CHC involves the culture. The uplifting workplace environment at the CHC was full of continuous encouragement for learning and growth, as well as the consistent recognition of accomplishments among the staff. I cannot make enough positive remarks about the working climate, and I will carry an inspiration for a similar environment in my future endeavors. Following this experience, I plan to graduate with a Bachelor of Science in Population Health from Manchester University and later, attend graduate school for a Master of Public Health or a Master of Science in Nutrition and Nutrigenomics. Thank you to the team at The Community Health Clinic and The Community Dental Clinic for an exceptional summer.

CLINIC NEWS & UPDATES

GRANT AWARD

The Community Health Clinic was recently awarded Non-Profit Assistance Grant from the LaGrange County Community Foundation for our new Donor Management Software. Through their generosity we are able to update our current practice of donation tracking and replace it with a more detailed and efficient methodology.

ELAINE'S RETIREMENT



We wish to give our dietitian, Elaine Wakefield, a warm thank you and a heartfelt goodbye for all of her hard work and years of service here at the Clinic. This past September Elaine

officially retired from the CHC with plans to travel and enjoy more time with her family and friends. Elaine was a tremendous asset to the Clinic and was always willing to go above and beyond for all of her patients. The CHC wishes her the very best and nothing but happiness in her future endeavors.

COMMUNITY IMPACT

Since our last newsletter, the staff here at the CHC have not only been busy with their day-to-day work but they have also been busy educating the community and surrounding communities about the special work the Clinic does. Dr. Z and our Newborn Screening

Coordinator, Jody Werker, spent some time in Nappanee doing a parents' meeting in September for the Blessed Beginning's midwives speaking about the importance of newborn screening.

Two clinic education events also took place, one being held here in Topeka, as well as a new area for us, Newaygo, MI. Both of these events were a success for helping to spread the word about our clinic's services and mission.

Our Care Coordinator, Pam Deetz, has kept herself busy with attending the Cub Cadet program at the Topeka Elementary School where she was able to provide resources about the Clinic. Pam also hosts a PKU moms' group held at the Clinic one Saturday every other month.

Most recently, a few of the Clinic's staff were provided an opportunity to speak to the 8th grade class at Westview Elementary School. Staff were able to talk about the role the Clinic plays in the community as well as giving a basic "what is genetics" overview.

RESEARCH UPDATE



Sharon Chupp,
Research Coordinator

It has been rather busy in the research department over the past several months. First of all, we are very excited to have Annie Brinson join our team! Her experience as a clinical research coordinator and

expertise in the many details of research are a great asset to The CHC's mission. Annie has quickly acclimated to The CHC family and is getting to know our patients and supporters.

The CHC is part of a clinical trial that is looking at the effects of a new drug in adults with propionic acidemia (PA). Our team enrolled and dosed the first person in the US, affected with PA, to be treated with the new drug. The study treatment phase is only 6 weeks long, but there are many elements involved in this type of research including detailed record keeping, weekly office visits for the patient, and at least three blood draws per week. We are especially grateful to our patient and the family for taking time to participate in this important work.

While the above study is still open for enrollment, we are also working on a couple other projects. One of these is a drug study for adolescent and young adults (ages 12-18 years) affected with PKU. The drug in this trial is already FDA approved for use in adults; this study is to verify the safety of its use in younger people since it can greatly reduce the need for food restrictions that people with PKU have to follow. We have several additional studies in our pipeline and will share information here in the near future. Participating in clinical research is part of The Community Health Clinic's mission. We believe patient-focused research is vital to advance medical knowledge and improve care for our patients and the community in general. If you or a family member is interested in learning more about any study, please call The CHC and ask to speak to Sharon or Annie.

Community Dental Clinic

Deborah Jurgielewicz, Operations Director CHC, Inc.

The Community Dental Clinic continues to apply grant funding from The Indiana State Department of Health (ISDH). When eligible, we are able to extend dental services at little to no cost to the patient. In addition, we use the funds to promote the importance of good oral health habits. This month, we started a "CAVITY FREE CLUB" board. The purpose of the "club" is to promote awareness on how proper dental hygiene can improve our smile. We do this by giving

recognition to patients, 13 and under, who are cavity free at their checkup. Our patients write their name on a "tooth" and it is placed on our board for the month. It is displayed in our waiting room in the hopes of providing inspiration to others. They also earn the reward of selecting a special prize from our prize box. At the end of the month, a grand prize winner is selected and earns a battery operated toothbrush and toothpaste. Each month, the board is decorated and updated



with new dental facts. We thank ISDH for recognizing the importance of our program! For further information about our program, please contact Lily Yoder at 260-768-7918.



The Community Health Clinic

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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.

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

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