

DDC Clinic Chronicle

THE NEWSLETTER OF DAS DEUTSCH CENTER FOR SPECIAL NEEDS CHILDREN

Research Scientist on Board

In October we had the pleasure of welcoming research scientist Dr. Baozhong (Bao) Xin. Dr. Xin, a native of the Shandong province in Eastern China, received his medical degree at Beijing Medical University, and his PhD in molecular biology and viral oncogenesis from the University of Hong Kong. He is currently a post-doctoral fellow in the Cancer Biology and Cancer Genetics Program at Case Western Reserve University. Research projects have included the identification of colon cancer causing genes or biomarkers for early diagnosis and treatment of colon neoplasia. Two novel colon cancer specific genes were identified and show promising prospects for use in the early diagnosis of colon cancer and mass screening of populations at risk. Further study of these genes will develop therapeutic drugs to help in the intervention and spread of colon cancer. Dr. Xin's

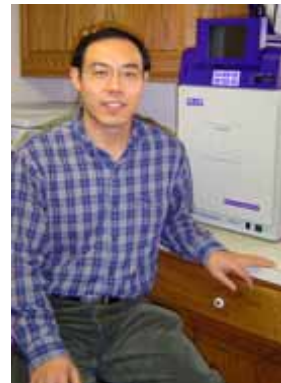
work also encompasses the study of the Epstein-Barr virus. Additionally, he has collaborated on numerous publications and scientific presentations.

Currently, Bao is working on getting DDC Clinic's research lab set up based on the needs of the clinic. Learning as much as possible about the disease identified within the community is the first step in developing the necessary biological assays or protocols that will assist in the diagnosis of these diseases. Once the lab is set up, and within six months, Bao hopes to have DNA test methods established for at least 20 diseases in order to make their diagnosis more efficient and effective. Additionally, he will be working to develop other types of tests (blood, saliva, etc.) to further disease diagnosis. Three years from now, the goal is to Bao believes we will have found the answers (causes)

of some unknown diseases using cutting-edge technology in Biological Sciences. He also predicts that our research will lead to a better understanding of the cause, progression, and treatment of several key diseases within the community.

The unique opportunity and challenge that DDC Clinic presents is what intrigues Bao the most

about working with us. He welcomes the opportunity to work closely with the community and our patients. "Everything we are working on is some form of knowledge and technique application in order to help disease diagnosis, education, and patient care," he says. "From these practices, we can learn more and use it to help others in need—both locally and worldwide." In his spare time Bao enjoys family life, music, traveling, and sports (his co-workers enjoy teasing him about his love of eating and shopping, too!)



Dr. Baozhong Xin sits in the clinic's lab by a Biodock-it imaging machine used to show DNA documents.

DDC Clinic Implements Rehabilitation Program

DDC Clinic is pleased to announce that, with the support of a grant awarded through the Mattel Children's Foundation, we are now offering a rehabilitation program at our facility. This new program will promote the participation of children in daily activities and routines in the home, school, and community through pediatric occupational therapy (O.T.) and physical therapy (P. T.)

Pediatric physical therapy focuses on the development of gross motor skills and the enhancement of a child's ability to explore his or her environment. Our patients will obtain these skills through play-oriented activities that help to improve strength, range of motion, balance, endurance and/

or motor planning. Pediatric occupational therapy focuses on fine motor skills including hand and finger coordination, grasping, handwriting and scissoring, motor planning skills, and/or feeding and swallowing abilities. The goal of a pediatric occupational therapist is to help a child function more independently by aiding in the development of fine motor, play, self help, and/or school-related skills.

Providing the therapy services will be Katy Horwitz, a licensed physical therapist with 10 years of experience, and occupational therapist Amy Zlotnik, also with 10 years of experience. Both types of pediatric therapists support children and their families from infancy through adolescence

by providing evaluations, family education, home program development and the implementation of a wide variety of interventions and supports. Parents and families play the primary role in their child's development, however, the skills and support of a pediatric therapist may help a child reach higher levels of independence.

Katy and Amy will be at the clinic Wednesday afternoons. If you are interested in learning more about these therapy services or would like to schedule an evaluation for your child, please contact the DDC Clinic office at 440-632-1668.

President's Letter

As you settle down to read the latest news from DDC Clinic, the wonders, delights, and miracles of the holiday season are behind us – along with all of the hustle and bustle, too – (phew!). While this might normally be a time to slow down, here at the clinic we are quickly moving deeper into the next level of our mission – research.

In October we welcomed Dr. Baohong Xin (Bao) as our research scientist. Bao has accomplished a great deal in the short time he has been with the clinic; he is setting up a functional laboratory and has already established a DNA test for Ganglioside GM3

Synthase Deficiency. Additional research and the development of many other DNA tests are on the way in this first stage of Bao's work.

As exciting as this work is, we are ever-mindful of the trust that our patients and their families have in us. Everything we do connects to our mission to enhance the quality of life of special needs children with metabolic and inherited disorders through early diagnosis and treatment, research, and education. The relationships we have built in the communities we serve and with the medical professionals connected to those

communities and beyond, ensure the success of our mission.

Even as we move forward, we pause for a moment to say thank you to the many supporters of DDC Clinic. You are our foundation; with your help we have a base that is strong enough to support the work of the future. We also say thank you for your trust in us.

Sincerely,

Darla C. Klein
Board President

Wish List

- **Chromatography double-sliding door refrigerator**
- **Ultra-low temperature freezer (to -80° C)**
- **Liquid nitrogen tank**
- **DNA Sequencer**
- **8-1/2 x 11 copy paper**
- **CD-RW CD's**
- **All-in-One color inkjet printer**

Know of any property?

DDC Clinic has outgrown its current home and is looking to acquire 3-5 acres in Geauga County to build a new clinic and research facility. The property needs to be accessible to our patients and a quiet setting is preferred. Improvements are not required. If you know of any land available that would fill our needs, please call us at 440-632-1668.

Is It a Cold or the Flu?

Symptoms	Cold	Flu
Fever	Rare	Usual; high (100° F to 102° F; occasionally higher, especially in young children); lasts 3 to 4 days
Headache	Rare	Common
General Aches, Pains	Slight	Usual; often severe
Fatigue, Weakness	Sometimes	Usual; can last up to 2 to 3 weeks
Extreme Exhaustion	Never	Usual; at the beginning of the illness
Stuffy Nose	Common	Sometimes
Sneezing	Usual	Sometimes
Sore Throat	Common	Sometimes
Chest Discomfort, Cough ...	Mild to moderate; hacking cough	Common; can become severe
Treatment	Antihistamines; decongestants;	Antiviral medicines-see your doctor
	Nonsteroidal anti-inflammatory medicines	
Prevention	Wash your hands often.	Annual vaccination; antiviral medicines
	Avoid close contact with anyone with a cold	see your doctor
Complications	Sinus congestion; middle ear	Bronchitis, pneumonia; can be life threatening
	infection; asthma	

U.S. Department of Health and Human Services; National Institutes of Health; National Institute of Allergy and Infectious Diseases; 9/2005

Glucose-galactose Malabsorption – Joseph’s Story

Glucose-galactose malabsorption is a rare genetic disease and most people, including many physicians, have never heard of it. We described this disease in our last newsletter; since then, a local Amish family was able to follow the lead and identify this disease in their newborn baby Joseph. They called us, and with our help, we were able to confirm the diagnosis. Joseph has recovered well from the disease and we would like to share his story along with his family's joy (ours, too) over his recovery.

On an early Friday morning in August, an anxious dad called our clinic. “Dr. Wang, we read the newsletter, we think our newborn has it.” Barely two weeks old baby Joseph was not doing well. The family suspected he had glucose-galactose malabsorption, a disease detailed in our previous newsletter (affected patients cannot properly break down regular carbohydrates from breast-milk, formula, or other foods; when this happens they pass into the stool in large amounts.)

Joseph, weighed 9 pounds, 7 ounces at birth—heavier than any of his seven siblings at birth! He was a fairly vigorous baby before starting to have serious problems. At three days old, he developed watery diarrhea. His belly became distended and he had quite a bit of gas. At first, the parents thought that Joseph might be allergic to milk, which would eventually get better—they hoped. As time passed, Joseph did not improve and his diarrhea got progressively worse—up to 10 times a

day. It was at about that time that they read DDC Clinic’s newsletter.

The parents talked with each other, “What they’re describing sound like our baby.” They talked with relatives and realized that although none of their own children had this disease, both sides of the family had children with it. They decided they couldn’t wait any longer when Joseph weakened and became restless. The mother told her husband, “We need to get him checked right away.”

In a clinic exam room, Dr. Wang listened carefully to Joseph’s story and examined him thoroughly. He told the family, “I’m glad you brought him over, I have to agree, I believe he does have glucose-galactose malabsorption and we may have to admit him to the hospital.” At just two weeks old, Joseph’s weight was down to 7 pounds, 10 ounces, and he was moderately dehydrated. This pattern of chronic and persistent diarrhea, often leads to nutritional wasting and severe dehydration, and can be life-threatening if not identified and treated properly.

Luckily for Joseph, much is known about this disease compared to a few years ago. Once diagnosed children usually do very well. They are put on a special formula and the diarrhea stops almost immediately. As Dr. Wang reassured the parents he remembered something—sitting in the clinic’s basement were two cases of the special formula Joseph needed—they had been ordered for

another family but he told them, “We can borrow them for now and get him started on it right away.”

After a long discussion and careful planning, Dr. Wang decided not to admit Joseph to the hospital. Instead, he came up with an outpatient care plan—the special formula was to be mixed with a measured amount of extra water; this would correct Joseph’s dehydration. Joseph’s dad used a neighbor’s phone to call Dr. Wang later that evening. From that conversation it was clear that Joseph was doing much better—he was resting comfortably and wasn’t very fussy at all; his belly was much better with less gas as well. “How’s his diarrhea?” Dr. Wang asked. “Well,” the dad said, “we can’t tell, he hasn’t had a bowel movement since we left your office.” With a short pause, Dr. Wang asked, “Are you telling me his diarrhea has completely stopped?” The dad replied, “I guess I am.” They both laughed with joy! On Monday, when Joseph returned to DDC Clinic, he was completely rehydrated and happy.

Joseph recently had his four-month check-up with us—he weighed nearly 16 pounds – a big, healthy, happy baby!

You can find more detailed information about this disease in our last newsletter. Extra copies are available in our office.

**The patient’s name has been changed to protect confidentiality.*

Mysteries and Quick Tips about Glucose-galactose Malabsorption

Mystery: *When affected children have diarrhea, from the disease itself or from a viral infection, Pedialyte and other oral rehydration solutions do not help and diarrhea gets worse.*

Quick tip: Sugar in these conventional oral rehydration solutions makes diarrhea worse—use homemade “Pedialyte”, don’t add sugar.

Mystery: *When affected children take antibiotics they almost always have diarrhea.*

Quick tip: Diarrhea may not be a side-effect of the antibiotics, rather it may be from the sugar added to the antibiotic liquid. In order to avoid diarrhea, the doctor may have to request that a pharmacy make sugar-free antibiotic liquid.

DDC Clinic Fundraising Events Raise Monies, Promote Fellowship

Did you attend one of DDC Clinic's summer and fall fundraising events? If you did, you are not alone. The community's response to the following events was overwhelming, collectively raised nearly \$70,000 for our clinic and its patients! A big DDC Clinic thank you to our sponsors, donors, attendees, and volunteers that helped with each of these events! We know how truly blessed we are to have all of you behind us, helping to carry out our mission.

Traditions & Treasures (July and October)

These two evenings featured a lot of fun, fellowship and friendship. Guests were treated to stories about the Amish culture and lifestyle, a stop at an Amish school or workshop, and a traditional Amish wedding dinner complete with homemade desserts. Discussions between "Yankees" and Amish throughout the evening promoted greater understanding and drew the two groups closer as each began to appreciate the scope of how much there is to share on both the human and scientific sides. The realization that we truly are all part of one big family profoundly affected many in the group. Especially on the part of the visitors, there was a great reluctance to end the evening and head for home.

We would especially like to thank our Traditions and Treasures title sponsor: **Turben Developmental Services**, with their support and that of many volunteers, these two evenings were successful beyond what we had imagined and accomplished more than we ever thought possible.

Bow Shoot (September)

Our September bow shoot can be described in many ways—none of them very flattering! We are pretty sure that on the day of our bow shoot there was not a rainier, damper,

muddier day in all of September! The tractor brought in to haul gravel was able to help only a little. As you can imagine, the non-stop rain and ankle-deep mud kept attendance very low but those who did show up, and managed to stay even a little dry, said they had a good time despite the weather. Highlights of the event included raffles for numerous hunting-related items from muzzle loaders to scopes to tree stands—with such a low attendance the odds of winning one of these great items were increased greatly. Many were seen soothing their dampened spirits (and their bellies) by enjoying lots of hot coffee and a chicken barbeque that luckily, was served under a tent.

Thank you so much to everyone who worked so hard to organize this event, to those of you who braved the weather to you're your support for the clinic, and to the sponsors and donors who supported us by giving donations of food, sporting equipment, and other raffle items. Special thanks to Great Lakes Outdoor Supply who also assisted in securing sponsors and the coordination of the event. We appreciate all of you and your efforts greatly!

Amish Country Auction (November)

DDC Clinic's fifth annual country auction was truly provided for a fun-filled evening—

visiting with friends, purchasing some great items, and eating were highlights for all who gathered. With over 1,000 attendees, the majority of them Amish, the event itself provided great entertainment. Anyone in the market for a new single buggy, some maple syrup, a quilt, a can of WD-40, or a pony came to the right place—these items and many more were sold to the highest bidders. Rows and rows of baked goods were emptied quickly and the crowds in the lunch stand area never died down. Thank you to all of our bidders, organizers, and volunteers that helped make the evening so successful.

As a twist on the evening, DDC Clinic offered free blood glucose and cholesterol screening on a first come, first serve basis. We admit, though, that our goal of performing 200 screenings was a bit lofty. When the screening machine jammed on the first test we began to worry! We're blaming any high test numbers on the large number of delicious fry pies many admit to eating right before the tests were performed! Special thanks to Leah Nye, DDC Clinic's nurse practitioner, and Dr. Wang for working tirelessly through the evening to get as many screenings done as possible. We are so happy to have been able to provide this service during that evening and plan to offer it again at next year's event (with some changes to make things go smoother, of course!)

DDC Clinic Presents "Medical Home Concept"

Many visitors to DDC Clinic comment on its comfortable and homelike atmosphere—not something found in many offices across the nation. Focusing on our patients the clinic was designed with their needs in mind. Upon entering the facility patients, families, and visitors feel welcomed. The clinic's relaxing setting puts parents at ease and invites children to play in a waiting room that looks and feels more like a living room. Here they have found what has not been found elsewhere, a place they can call home, a place where they are encouraged to discuss every aspect of their child's care. This fits closely with the new concept of a "medical home" that is strongly being advocated by the American Academy of Pediatrics (AAP). The medical home is a model of special care. The care received by families and children with special needs should be "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective."

Dr. Wang summarized some of our findings over the past three years and our use of the medical home concept in an October poster presentation at the annual meeting of the American Society for Human Genetics. Over the years, we have seen that the use of the medical home concept increases family and patient access and coordination of specialty care, educational services, out-of-home care, family support and other public and private community services. We have also seen a shift in the higher, complex visits to moderate complexity visits, sick visits have decreased and preventative visits have increased markedly—all of which leads to improved patient wellbeing as both medical and non-medical needs are met. This concept is cost-effective and care-effective.

Matching Funds Continue to Be Critical

With the Holiday season behind us for another year, most of us are looking forward to a healthy and prosperous New Year. But there are children, right here in Northeast Ohio and beyond, that have severe challenges to overcome every day of 2006. These children are suffering from metabolic and genetic diseases.

DDC Clinic is dedicated to helping these children through programs like "Love, Faith, and Family", a four-year project funded in part by the prestigious Robert Woods Johnson Foundation (RWJF). Most importantly, **you can help** us continue providing education and critical care to improve the quality of life for these children.

The "Love, Faith, and Family" project focuses on three main objectives: to

provide outreach for promoting newborn screening of genetic and metabolic diseases, to provide early diagnosis and optimal care of the diseases, and to maximize the health potential of individuals and the community.

Thus far, under the auspices of the grant, the Clinic has provided services to 180 families, 225 patients, hired a full-time nurse practitioner to assist with therapies and patient care, and held more than five sub-specialty clinics on-site.

As a Local Initiative Funding Grant, RWJF will match funds raised by DDC Clinic up to \$411,297. We must raise these dollars or face losing the foundation match. With the generosity of our supporters we have had great success to date. However, we

MUST still raise \$50,000 by June 2006 to complete our commitment.

Please consider the value of any gift you give – that it will double the dollars that can be used to make life less challenging for children with special needs.

Won't you start the New Year by making a gift that will double in its capacity to help children? In addition to cash donations, DDC Clinic staff would be happy to discuss with you gifts of stock, securities, or bequests.

Please call the Clinic office at 440.632.1668 for more information or to schedule an appointment with our staff.

CORRECTION

Despite our best efforts, there were errors in the listings of our valued donors in our recent 2004 Annual Report. We would like to re-print the corrected category of our \$25,000 & Over supporters. Our apologies to everyone affected, and our sincere gratitude again for your generosity.

\$25,000 +

The Amish Community
Geauga Community Development
Kinetico, Inc.
Mr. & Mrs. Gordon Safran
United Way Services
United Way Services of Geauga County

Dr. Heng Wang, DDC Clinic medical director presents James Schill (l.), President, and Bob Toth, Chief Executive Officer of Middlefield's GoldKey Processing, Inc. with a plaque of appreciation for their support of DDC Clinic and its mission.



Food and Fun Day Spices Things Up

Yummm! Nachos! Whether you like them or not, the majority of you have had the opportunity to try them to decide. However, anybody with phenylketonuria (PKU) or propionic academia knows that nachos do not make the list of approved snacks. The protein in the meat, cheese, tortilla chips, and many other nacho "staples" are what present the problem. Patients with these two diseases don't dare give into temptation lest they risk behavior changes and possible

mental retardation (based on the age of the patient.)

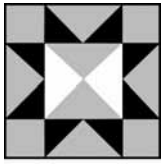
Recently, however, in conjunction with the **Department of Endocrinology and Metabolism, from Rainbow Babies and Children's Hospital**, DDC Clinic was able to offer many of our PKU patients the opportunity to do just that at our second Food and Fun Day featuring low-protein foods and creative cooking. Participants enjoyed a nacho bar complete with

all the fixings and a dessert bar stocked with low protein ice cream and brownies. One participant commented several times that she couldn't believe how wonderful the food was. It was really a fun afternoon of dining, cardmaking and fellowship.

Thank you to **SHS Foods, Inc.** who donated food items for the participants to take home. Low-protein food items are expensive—a small package of macaroni and

cheese costs well over \$6.00. DDC Clinic, in partnership with the **Christ Child Society** and several other foundations, provides low-protein food at substantially lower costs to our patients who depend on this specialty food to maintain an appropriate diet, maximizing their health and wellness.

Life is not easy for any of us. We must have perseverance and, above all, confidence in ourselves. We must believe that we are gifted for something, and that this thing...must be attained. -- Marie Curie



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Das Deutsch Center

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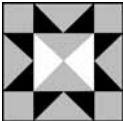
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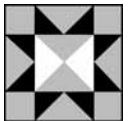
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MISSION STATEMENT: To enhance the quality of life for special needs children with metabolic and inherited disorders through early diagnosis and treatment, research, and education



DDC Clinic
Calendar of Events



Thursday, January 12 2006 – Holmes County Outreach Clinic, Holmes County Training Center

Thursday, February 2, 2006 – Holmes County Outreach Clinic, Holmes County Training Center

Saturday, February 11, 2006 – Food and Fun Day, Burton Fairgrounds

Friday, March 17, 2006 – Neurology Clinic, DDC Clinic

Friday, April 28, 2006 – Sixth Annual Patchwork Benefit Auction & Dinner, Signature of Solon

I will gladly support DDC Clinic. Enclosed is my check.

My Name _____

Make checks
payable to:

Please make the donation in Memory / Honor of:

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Name _____

City _____ State _____ Zip _____

Occasion _____

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DDC Clinic
P.O. Box 845
Middlefield, OH
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A small body of determined spirits fired by an unquenchable faith in their mission can alter the course of history--

Mohandas Gandhi