

DDC Clinic Chronicle

Issue 1—2005

THE NEWSLETTER OF DAS DEUTSCH CENTER FOR SPECIAL NEEDS CHILDREN

Fifth Annual Patchwork Benefit Slated for April 9th



This Amish-made wooden schoolhouse was one of last year's top sellers in the live auction. Join us to see what this year's will be!

DDC Clinic's Fifth Annual Patchwork Dinner and Auction is quickly approaching. Mark **Saturday, April 9th, 2005** on your calendar and plan to join us for an evening of food and fun.

Last year's event netted over \$75,500 and we expect this year's to be the most successful yet thanks to the continued generosity and enthusiasm of our wonderful supporters! As always, 100% of the auction proceeds go

towards helping DDC Clinic to continue providing its groundbreaking and lifesaving services.

From our Inaugural Event in 2000 at Patterson Fruit Farm and Orchard Hills Golf & Country Club, through the delightful evenings at the EOUV Club, to last year's event at Gilmour Academy, we look forward to an incredible evening at The Crystal Brook Farm in Chagrin Falls.

What makes DDC Clinic's Patchwork Event so unique is its combination of Yankee (non-Amish) and Amish traditions and the variety of auction items offered during the live and silent auctions. As has become Patchwork's signature, guests can expect truly one-of-a-kind items made for us by our Amish and Yankee friends. This year's opportunities include a fantastic red, white, and blue quilt; the chance to design your own piece of furniture handcrafted to your

specifications; as well as many other gorgeous pieces of furniture made specifically for Patchwork by DDC Clinic board members, their families, and friends. We have had many other fantastic items donated—too many to list here (but perhaps we should mention that **OSU football tickets** are back by popular demand!)

Ms. Lee Jordan, NewsChannel 5 "Live on Your Side" Co-Anchor and the On Your Side Health Specialist, will join our favorite auctioneer, Dave Rennolds, in

emceeding the Live Auction Event as they take the highest bids!

Our heartfelt and sincerest thank-you's to the phenomenal individuals and businesses that continue to support DDC Clinic through their generous donations of services, items, time, and energy!

Are you interested in joining us? Do you have an item to donate for the auction or would you like to become a sponsor? Please call the DDC Clinic office and let us know—440-632-1668!

We hope to see you there!

EVENT HIGHLIGHTS

- Cocktails and dinner
- Amish baked goods and Spring flowers for sale
- Live Auction Items -
 - Plan-Your-Own-Event at Patterson Fruit Farm
 - OSU Football Tickets
 - Goodyear Tire & Rubber Blimp Ride—*Sprit of Goodyear*
- Silent Auction Items -
 - Shaker boxes and benches
 - Quilts
- Raffles - \$500 cash or handcrafted cedar chest

Catering by Cucina Rustica

Geauga Library Foundation Provides Reading Materials

Patients and parents visiting DDC Clinic have more help available to them than ever before thanks to a generous donation recently made by the **Geauga Library Foundation**. The foundation donated more than 30 books valued

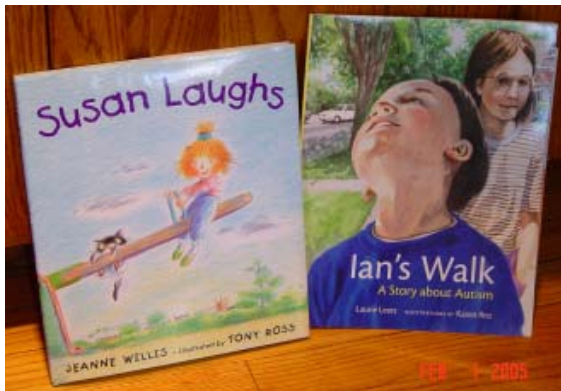
at approximately \$500 to DDC Clinic's small patient and parent library—nearly doubling the materials available. The books, which are available for check out, cover a wide range of topics and are geared toward families and others who are interested in learning more about specific diseases, looking for ways to understand or cope with special needs children, or seeking support through the shared perspectives of other families experiencing similar obstacles.

Paul Newman, president of the Geauga Library Foundation, and Anne Prusha, foundation spokesperson, visited DDC Clinic in mid-December 2004 to present the books to Dr. Wang, the clinic's medical director. "We are so pleased to receive this grant from the Foundation. These books will help us

continue to provide the most up-to-date information to our patients and their families. This need has existed since we opened in 2002 and bit by bit we are working hard to fill it," said Dr. Wang.

Resources are available in the form of books, magazines, brochures, and videos and cover subjects relative to children with special needs such as daily care, nutrition, schooling, parenting, family life, coping, and much more. The library is updated almost quarterly and turnover rate of the materials is increasing. "We're happy to do it," said Mr. Newman, "Where there's a need, there's a deed."

Anyone interested in learning more about materials available from DDC Clinic's library or in making a monetary or material donation for the library may contact the DDC Clinic office at 440.632.1668.



Just two of the over 30 books recently donated to DCC Clinic through a grant funded by the Geauga Library Foundation.

President's Letter

Dear Friends:

The winter has been mild. Recently, we have had sunny days in the fifties. It is easy to imagine the smell of spring in the air. Those of us with more winters behind us than we would like to admit know that winter is not done with us yet. Another cold blast is due from across the lake and there will be a solid cover of snow in the sugar bush before spring truly arrives.

Each March the board of directors celebrates the anniversary of the clinic. It is a good time to recognize achievements, thank the people who made those achievements possible, and look to the future.

Dr. Wang, Julie, and Leah now provide primary medical care to over 170 children. The excellent care provided by the clinic staff makes a dramatic difference in the quality of life for many families. Over 40 different genetic disorders have been identified in the Geauga

Settlement. Several of the disorders are rare; one has never been described before. Dr. Wang has published his findings in peer-reviewed journals and both he and Leah have presented their findings at an international conference.

This year the clinic received record support from the community, corporations, and charitable foundations. The Robert Wood Johnson Foundation grant and the accompanying matching funds will enable DDC Clinic to better serve the educational needs of our patient's families. The success we have experienced comes with even more responsibility and higher expectations. In our immediate future we plan to build a research laboratory, hire a research scientist, and expand our services to more families here and in Holmes County. With your continued support, success is sure to follow.

There are many people to thank who make our work possible; the

families who entrust to us their children's care; the individuals and the families that participate in the clinic's research. We are grateful for the hundreds of volunteers who make our fundraising events fun and successful. Dr. Wang, our nurse practitioners, Leah and Julie, and our office team, Terry and Michelle, are tireless in carrying out the mission of Das Deutsch Center. I personally wish to thank the board of directors and our officers who have attended hundreds of meetings, donated their time and handiwork, and who have freely offered financial support. The accomplishments of DDC Clinic would not and could not have happened without the enormous amount of creativity and dedication displayed by its board of directors.

Thank you,

Tom Stone
President

Meet Julie!

Welcome to our newest member of the team—Julie Renner, a pediatric nurse practitioner and certified early-intervention specialist from nearby Orwell. Julie's resume boasts many accomplishments including a Bachelor's and Master's degree in nursing from Kent State University along with postgraduate work in special education. Julie is also a certified infant massage instructor and serves as part-time faculty at Youngstown State University through Beeghly College of Education.

Julie's work experiences with the Bureau for Children with Medical Handicaps, Help Me Grow, Tod Children's Hospital, Trumbull County Health



Department, Trumbull County Board of MR/DD, and the Mahoning County Board of MR/DD, will serve DDC Clinic well as patient load increases and clinic services are expanded.

"I am thrilled to be working at DDC Clinic. It is very rewarding to me to be able to utilize my nursing skills and experiences in caring for children with special needs," said Julie. In her spare time Julie can often be found trying out her green thumb on vegetable and flower plants from her greenhouse or doing needlepoint or jigsaw puzzles.

Welcome, Julie, we are so glad to have you as a member of the DDC Clinic team!

Traditions and Trzasaurs

A distinct and delectable evening in the country!

This event promises to be one of the most unique benefits you will ever attend! If you enjoy country ambiance, cultural exchange, down-home cooking, and an event that is a little more personal and a little less pretentious – this event is for you! We promise you will end the evening feeling warm and fulfilled.

On three select days in 2005, DDC Clinic will host an exceptional evening for a limited group of friends. Beginning with a wine and cocktail reception hosted at the quaint Red Maple Inn in Burton, guests will have the opportunity to learn about some timeless Amish customs and enjoy good company. A chartered coach will then transport guests to a private Amish home within The Geauga Settlement. No evening will be the same—each dinner will be a different experience.

Come hungry! Guests will be served a customary Amish

Wedding dinner in a typical Amish home and are guaranteed a personal glimpse into the Amish life and its culture.

We are excited to offer you this unique opportunity to meet some new Amish and Yankee friends while supporting our mission of providing medical care to children with metabolic and inherited diseases.

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Evenings:

- Saturday, May 7
- Saturday, July 16
- Saturday, October 22

Tickets:

- Patrons – \$150 each
- Friends – \$100 each

Please note - Tickets are very limited. Send or call in your reservation today to DDC Clinic.

Clinic Update – We’re Expanding!

Coordinated therapy service is one of the more urgent needs of our children. Did you know that many of our patients currently do not have access to therapy services? It is our goal to add this much-needed therapy to DDC Clinic services in 2005. The planned multidisciplinary therapy clinics will include physical, occupational, and speech therapies. Children will be able to receive any combination therapy services in one visit. Therapists will interact as a team to develop therapy goals that are complementary and holistic.

A Holmes County outreach program is another DDC Clinic expansion plan. The Geauga Amish settlement is a daughter settlement of the larger Holmes County settlement—the two communities retain close ties. The DDC Clinic board and staff believe that through the sharing of knowledge and experience gained in the Geauga community, we can improve the health and wellness of the children in the Holmes County area. However, during the planning stage, an early-identified problem was the difficulty for families in accessing our services from distant communities. Through this outreach, many families far from DDC Clinic will be able to receive service closer to their homes.

DDC Clinic expansion is the immediate focus of our future. DDC Clinic has seen tremendous growth in the number of children and families served since opening in 2002. The types of services needed by these children have also increased. To meet their needs, new staff and programs have been added, increasing the need for space for personnel, equipment, and materials. Our beautiful 1,800 square-foot building met our needs well during the start-up phase of the clinic, but is now reaching its limits with the growth we have experienced. Thankfully, with the foresight of a visionary board of directors, plans for expansion were included in the original clinic blueprint. However, our rapid growth has exceeded our initial estimates. We are seeking financial support to quickly move our clinic to the next level.

Recent Fundraising Events Raise Almost \$63,000 for Clinic Services

Bow Shoot - In September, DDC Clinic held its first-ever Bow Shoot at the Top Gun Facility in Middlefield. Sponsored by **Great Lakes Outdoor Supply**, the event drew over 200 supporters and brought in proceeds of over \$7,000.

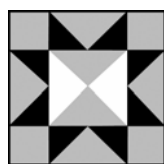
Participants enjoyed a wide variety of activities including bow shoot tournaments, shotgun sling shoots, and trap shoots. In addition young attendees were able to try their hand at a fishing derby.

Special thanks to all of the generous community businesses and individuals who offered their support to this fun family event. Planning for next year’s event is already underway!

Amish Auction - The clinic’s Fourth Annual Amish Auction, held in Middlefield this past November, stayed true-to-form as a traditional-style, definitively country auction. Drawing a crowd of over 1,000, this predominantly Amish function continues to draw more and more ‘Yankees’ each year. From pony carts to horse-drawn buggies to quilts, this event had plenty to offer to those in attendance.

What an evening it was—we were excited (and very pleased) to learn that 2004’s event was the most successful ever—netting the clinic nearly \$56,000—almost \$20,000 more than the previous year’s event!

Thank you so much to those who participated and to those who donated items and services. Special thanks to event organizers and volunteers—your contributions and continued support are what helped make this event so successful!



Research Update –

The Latest Discovery

“We’ve been waiting 16 years for an answer,” said an Amish father whose four profoundly handicapped children thrashed spasmodically in wheelchairs and a crib before the watchful gaze of the visiting physician. ... “It may be too late for us ... but if we can help others with this center, we’ll gladly do that.” This story about love, hope and giving appeared on the front page of New York Times on June 20, 2002 and has touched countless people’s hearts since.

The children are suffering from an extremely rare disease called **ganglioside GM3 synthase deficiency**, a disease never before described in any medical textbook or medical literature. The results of our collaborative research with scientists in the U.S. and Europe have recently been published in Nature Genetics, (*Infantile-onset symptomatic epilepsy syndrome caused by a homozygous loss-of-function mutation of GM3 synthase*. 36:1225-1229; 2004.) a top medical journal. Soon after the scientific paper was published, several children with this same disease were diagnosed in another part of the country in addition to the 10 children affected in our area. These children live with uncontrollable seizures and feeding tubes and demand complete care in every aspect of daily life. Clearly, giving the diagnosis is not the end of the story. We are actively working with several research teams to further understand the disease and to find effective treatments with faith and hope...

“Unraveling the mechanism underlying this disease will not only increase our understanding of epilepsies but also illuminate the crucial function, now unequivocally established, of gangliosides in the brain.” –Dr. Richard L. Proia, Chief, Genetics of Development and Disease Branch, National Institute of Diabetes and Digestive and Kidney Diseases (NIH/NIDDK)



List of Metabolic and Inherited Diseases Managed by DDC Clinic (2004)



Adenylosuccinase (adenylosuccinate lyase, ADSL) deficiency (103050-R)	Hypertrophic cardiomyopathy
Alagille syndrome (118450-D)	Hypotonia, ataxia and developmental delay (?)
Amish albinism (606952-R)	Hypotonia, excessive height, pectus excavatum & mental retardation (Sotos syndrome?)
Amish brittle hair syndrome (234050-R)	Hypertriglyceridemia – lipoprotein lipase deficiency or apolipoprotein C-II deficiency
Autism spectrum disorders	Infantile lethal cardiomyopathy
Benign infantile hypotonia (?)	Juvenile glaucoma, failure to thrive and leukodystrophy (?)
Byler disease (211600-R)	Leigh syndrome (256000)
Cartilage-hair hypoplasia dwarfism (250250-R)	Leri-Weill dyschondrosteosis (127300)
Celiac disease (212750)	Microcephalic osteodysplastic primordial dwarfism, Type I (210710-R)
Cerebral palsy with late onset IgA nephropathy (?)	Maple syrup urine disease (248600-R)
Chicken breast disease (Amish nemaline myopathy) (605455-R)	Maternal phenylketonuria (PKU)
Chromosome 8p duplication	Mitochondrial respiratory chain complex IV deficiency (220110)
Cohen syndrome (216550-R)	Phenylketonuria (PKU) – phenylalanine hydroxylase deficiency (261600-R)
Congenital upper anomalies (sporadic)	Prolidase deficiency (170100-R)
Crigler-Najjar syndrome Type I (218800-R)	Propionic acidemia – propionyl-CoA carboxylase deficiency (606054-R)
Down syndrome	Pyruvate kinase deficiency of red cell (266200-R)
Familial cleft lip with or without cleft palate	Rett syndrome (312750)
Familial craniosyostosis (?)	Tarsal coalition
Familial deafness (?)	Troyer syndrome (275900-R)
Familial seizure with mental retardation (?)	
Ganglioside GM3 synthase (alpha 2,3-sialytransferase) deficiency	
Glucose/galactose malabsorption (606824-R)	
Hemophilia B – Factor IX deficiency (306900)	

Numbers: OMIM (Online Mendelian Inheritance in Man) numbers
R: autosomal recessive, D: autosomal dominant, ?: under study



We cannot all do great things but we can do small things with great love.

– Mother Teresa

Caring for Rare Diseases – Not Just Our Mission, but Truly Our Passion

What is rare disease? Rare diseases are defined in statute as any disease, syndrome, or disorder affecting fewer than 200,000 people in the United States. There are an estimated 6,000 rare “orphan” diseases that, combined, affect as many as 25 million Americans!

Barriers and challenges: People suffering from a rare disease often face incredible barriers when seeking medical care and related services. Equally, medical professionals are presented with enormous challenges in helping these patients. Diagnosing these diseases is the first challenge. At least 15%, or approximately 3.7 million people in the U. S., have to wait an average of seven years or more before a doctor reaches a diagnosis. Sometimes, the rare condition is never even named during a person’s lifetime. Once there is a diagnosis, patients are often forced to travel the long distances to academic hospitals to see the few specialists who focus on their particular disease. Financial costs associated with medical care of these rare disorders are often staggering—and emotional stress can be an additional burden.

National efforts: During recent years, it has become increasingly evident that the needs of those suffering with rare diseases have gone unmet. In 1983, Congress passed the Orphan Drug Act to address these unmet needs. A decade later, the Office of Rare Diseases was established at the National Institute of Health (NIH) to stimulate and coordinate research on rare diseases where none previously existed. It was not until 2002 that, for the first time ever, a sizable amount of federal funding (\$10.3 million) was made available for research on rare diseases. It is encouraging to see this move towards research funding, however, it is far from enough.

The importance of study of rare diseases has been long ignored. What is urgently needed is a new environment devoted to funding efforts to impact diseases affecting small communities of patients throughout the world. Ideally, this new environment would fully comprehend that the knowledge gained from studying these rare diseases could ultimately advance and contribute to understanding of common diseases. Enormous amounts of research on single-gene diseases

have provided clues to common diseases—clues that would have been difficult to find by simply studying the common diseases themselves. Many visionary scientists realize the value of rare disease research. In 2003, the National Disease Research Interchange drew prominent scientists from around the country for *The Genetics of Rare Diseases: Window to Common Disorders* conference. Last year, the distinguished speakers’ symposium of the American Society of Human Genetics annual meeting was entitled *From Rare Genetic Diseases to Common Pathways*.

DDC Clinic is our community’s effort to target rare diseases.

DDC Clinic is a unique collaboration between the Amish and non-Amish community, healthcare professionals, and research scientists. Caring for rare diseases is not just our mission, but truly our passion. We have fully committed ourselves to enhancing the quality of life for special needs children with metabolic and inherited disorders through early diagnosis and treatment, research, and education. Since we began providing services in 2002, we

have managed more than 40 rare diseases (see list), most of which were diagnosed through the clinic. We currently care for more patients with Cohen syndrome, prolidase deficiency, and GM 3 synthase deficiency than any other medical center in the world. This puts DDC Clinic in a very unique position. Genetic disorders seen in the Amish also appear in the general population. We believe that any gains made through research here have the potential to benefit special needs children throughout the world. Furthermore, we believe that our research contributes to the general knowledge of many common diseases in the general population, such as seizures, Parkinson’s disease, Alzheimer’s disease, lupus, and mental retardation. Indeed, our website (www.DDCClinic.org) has been linked as a resource by the National Organization of Rare Disorders (www.rarediseases.org) for families, researchers, and medical professionals around the world.

Please feel free to give us a call and let us share our passion with you!

Recent publications and presentations of DDC Clinic’s Collaborative Research

- Infantile-onset symptomatic epilepsy syndrome caused by a homozygous loss-of-function mutation of GM3 synthase. *Nature Genetics*, 36:1225-1229; 2004.
- Determination of prolidase activity using matrix-assisted laser desorption/ionization time-of-flight mass spectrometry. *Analytical Biochemistry*, 331: 224-229; 2004.
- A nonsense mutation of PEPD in four Amish children with prolidase deficiency. (Submitted for publication).
- Studying genetic diseases “without electricity”, presented at Ohio State Genetic Center Directors Meeting, 2003.
- Prolidase deficiency in four Amish patients: a novel mutation, presented in the American Society of Human Genetics 53rd Annual Meeting in Los Angeles, CA. *American Journal of Human Genetics*, 73: (Supplement) 447; 2003.
- Founder effect of phenylketonuria in the Geauga County Amish settlement of Ohio, presented in the American Society of Human Genetics 54th Annual Meeting in Canada, 2004.
- Infantile onset symptomatic epilepsy syndrome caused by a homozygous loss of function mutation in GM3 synthase, presented in the American Society of Human Genetics 54th Annual Meeting in Canada, 2004.
- Cartilage-hair hypoplasia in the Geauga County Amish settlement of Ohio, presented in the American Society of Human Genetics 54th Annual Meeting in Canada, 2004.

We appreciate the generosity of the following individuals, foundations, and corporations who have demonstrated their commitment to the children and families served in 2004!

\$50,000+

The Amish Community
The Elisabeth Severance
Prentiss Foundation
The Hershey Foundation
Robert Wood
Johnson Foundation

\$25,000+

Anonymous (1)
Geauga Community
Development
United Way Services

\$10,000 - \$24,999

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Gordon & Evie Safran
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Foundation

\$5,000 - \$9,999

The Edwin Northrup II Fund
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Thomas & Judith Phelps

John Phillips
Prestige Properties
Paul & Jane Stone
Alfred & Barbara Wilson, III

\$250 - \$499

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Funding Opportunity

Urgent—Matching Funds Needed!

We are very excited to have recently been awarded The Robert Wood Johnson Foundation's prestigious local initiative grant for our "**Love, Faith, and Family--Amish Genetic Disease Education and Care Program.**" This highly-esteemed, competitive, nationally-based grant supports an expansive plan to aid families in need through education, culturally-sensitive outreach, and genetic screening. This project will also allow DDC Clinic to extend its services into new communities. It will have significant local and regional impact.

Total project budget is \$822,594--The Robert Wood Johnson Foundation grant will provide \$411,297 of that total but only **if** DDC Clinic is able to secure matching support. The Cleveland Foundation, Hershey Foundation, Susan & John Turben Foundation, Evie and Gordon Safran, and Elaine Motylinski & Roger Vaccariello, round out the list of our original contributors and helped us to complete our first-year

requirement. *Thank you!*

DDC Clinic is now urgently requesting the support of additional donors to help us meet the upcoming year's matching fund requirement. Donors will be supporting a far-reaching project that will have a tremendous impact on children with genetic disease. Additionally, every dollar donated will be **doubled** in value as it is **MATCHED** by The Robert Wood Johnson Foundation! DDC Clinic needs to obtain approximately **\$300,000** in pledges in the next three years to meet this matching grant requirement.

Please consider donating to this worthy project. Any foundation, businesses or individuals interested in more details about this initiative or on how investment dollars can be doubled through this matching opportunity, please contact the DDC Clinic office at 440.632.1668. Checks for this project should be marked "RWJF Matching Grant."

Donors cont.

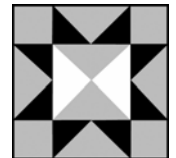
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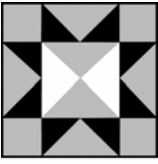
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We also wish to thank the generous people who have supported our special events, made in-kind service donations, volunteered their time, or given items to DDC Clinic.

Wish List

- \$125,000 for Clinic expansion
- Parking area expansion
- Handicap-accessible van
- Salary for van driver
- Equipment for gene-chip technology
- PCR and other Molecular Biology Lab Equipment



DDC Clinic
for Special Needs Children
 P. O. Box 845
 Middlefield, OH 44062
 440.632.1668 Phone
 440.632.1697 Fax

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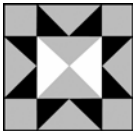
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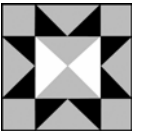
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MISSION STATEMENT: *To enhance the quality of life for special needs children with metabolic and inherited disorders through early diagnosis and treatment, research, and education*



DDC Clinic
Calendar of Events



- Saturday, February 26** – PKU Food and Fun Cooking Demonstration
- Thursday, March 3** – Holmes County Outreach Clinic, Holmes County Training Center
- Friday, March 18** – Neurology Clinic, DDC Clinic
- Thursday, April 7** – Holmes County Outreach Clinic, Holmes County Training Center
- Saturday, April 9** – Fifth Annual Patchwork Benefit Auction and Dinner
- Thursday, May 5** – Holmes County Outreach Clinic, Holmes County Training Center
- Saturday, May 7** – Traditions & Treasures Benefit Evening, Geauga County
- Friday, June 24** – Second Annual National Cohen Syndrome Family Meeting, DDC Clinic
- Friday, July 16** – Annual Golf Outing, Fowler’s Mill

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