



DDC Clinic
for Special Needs Children
A Non-Profit, 501(c)(3) Organization
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MISSION STATEMENT Das Deutsch Center for Special Needs Children provides care to children who have complex medical needs, which may be due to inherited, metabolic or genetic disorders. The clinic is open to all special needs children but will focus on the Amish community.

WE NEED YOUR SUPPORT! If you know of an individual, group, foundation, or business that might be interested in supporting our clinic and its services with a much-needed donation—please contact our office. Thank you for your consideration and support to help these special children. It is truly appreciated!

You're Invited to our Grand Opening Celebration!

Saturday, July 12, 2003

15809 Madison Road, Middlefield

9:00 a.m.—4:00 p.m.

11:00 a.m.—Ribbon-Cutting Ceremony
with Dr. Tom Stone, Board President
and Dr. Heng Wang, Medical Director

Entertainment!
Children's Activities and Play Area!
Beverages and light refreshments served!

The Second Annual Don Leach Memorial Golf Outing

Friday, August 15, 2003

4 Man Scramble

Grandview Golf Club
13404 Old State Road
Middlefield

\$100—18 Holes
(includes lunch & dinner)

\$45—Dinner only for our non-golfing friends

12:00 p.m.— Registration begins
Lunch is served

1:00 p.m.—Shotgun Start
6:00 p.m.—Dinner is served

Silent Auction begins

YOUR SPONSORSHIP MAKES A DIFFERENCE! *Your donation will grow 15 times as it is leveraged to help us earn clinic funds. Recognition as a caring community leader will be given at the event and in publications. Levels from \$250 to \$2,000 and up are available.*

For reservations or more information on sponsorship opportunities, please call the DDC office at 440-632-1668.

Join us for a FUN-FILLED day including food, golf, entertainment, silent auction AND raffle!

DDC Clinic Chronicle

Issue 2 - 2003

THE NEWSLETTER OF DAS DEUTSCH CENTER FOR SPECIAL NEEDS CHILDREN

WE'VE MOVED!

It is with great pleasure and much excitement we report, that after many months of thoughtful planning and hard work—we have finally moved into our new facility! Located at 15809 Madison Road (St. Rte. 528), we now have room to stretch and have left behind the days of borrowed exam rooms.



Still in need of a few finishing touches, our new facility has quickly become "home" for us.

We are so thankful for the many businesses and individuals who have donated materials and volunteered their time in helping to make such a world class facility for our patients. With

beautiful hardwood floors, hand-crafted gliders in our waiting room, a children's play area and comfortable exam rooms, we have truly found our "home" and we hope our patients will feel the same way, too.

Grand Opening
You're invited!

So many of you have played such a big part in helping us realize our dream of opening this clinic that we would like to invite you to join us on Saturday, July 12, 2003 for our grand opening celebration.

The event will be held from 9:00 a.m. to 4:00 p.m. with a special ribbon-cutting ceremony to be held at 11:00 a.m. Please stop by for light refreshments and a tour of the facility. We look forward to thanking you in person for your generosity and support over this past year. We hope to see you there!

We have a NEW LOGO! A special thank you and our sincere appreciation to **Paula Hershman** who has played an integral part in designing our new logo — the *Simple Star* pattern seen on the right is an example often found on Amish quilts. Quilting is most efficiently accomplished through teamwork and the bonds formed during the many hours it takes to complete a quilt often last a lifetime. We, too, strive for teamwork with both families and medical professionals and have begun forging bonds within our community that we hope will last a lifetime.



THIRD ANNUAL PATCHWORK EVENT: A CELEBRATION OF SUCCESS!

The E.O.U.V. Club in Novelty provided the perfect backdrop for DDC's recent Patchwork benefit dinner and auction. Guests could feel the anticipation building as they made their way to the silent auction pavilion. Many paused to admire the workmanship and fine details of the handcrafted log cabin playhouse being offered later that evening in our live auction.



Gathered in the main hall for dinner, our guests listen to musician Diane Hein sing her original song, "Patchwork of Love."

Once in the pavilion, guests were able to bid on a wonderful variety of silent auction items ranging from unique handcrafted items to gift baskets and certificates.

Later, a delicious meal added to already high spirits and paved the way for the live auction. Professional auctioneer Dave Rennolds, assisted by celebrity guest Dee Perry, from 90.3 WCPN's "Around Town"

segment, did an outstanding job. Bidding wars on several quilts, a handmade cherry bookcase, and the playhouse captivated the audience's attention. Competition for the log cabin was so fierce that its Amish

craftsman graciously agreed to make a second one—much to everyone's delight!

Thank you to our guests, the many businesses and individuals who donated items, our Patchwork committee, and our volunteers who helped to make our event such a success. Your generous support netted nearly \$50,000—all of which will help our special children by allowing us to provide enhanced care and treatment.

We are truly blessed with all of you who care so much and continue to support our cause. **Thank you!**

2002 Annual Report Highlights

Dear Friends:

It has been another successful year for Das Deutsch Center for Special Needs Children (DDC). As most of you know, in May 2002, we hired Dr. Heng Wang to be our medical director. Since then, he has made over 400 house calls, diagnosed several rare and difficult disorders, provided quality care to our patients, given support to their families, and increased our knowledge of genetic and metabolic disorders. Now, a year later, our facility is approaching completion and we will soon add a nurse to our staff.

Annual Audit: DDC's second annual audit was recently completed by Saltz, Shamis & Goldfarb, Certified Public Accountants. The DDC remained financially sound in a year when many charities had difficulty raising money. We continued to find success at raising funds, however, with the initiation of medical services, operating expenses increased significantly along with our need for increased financial support. The information below is taken from the audit.

STATEMENT OF ACTIVITIES

	2002	2001
Total Revenues	472,659	474,932
Total Expenditures	240,378	115,114
Net Assets	659,673	427,392

STATEMENT OF FUNCTIONAL EXPENSES

Program Services & Community Education	145,435
Management and General	33,916
Fundraising	61,027
Total	240,378

We anticipate a 12-month operating expense of \$365,000.

Patient Demographics: We currently care for over 90 children. DDC is on track to reach our first target of 150 patients in May 2004. The majority of our patients, as expected, come from Geauga (67%) and Trumbull (20%) Counties. Several children come from as far away as Columbiana and Richland Counties. Eighty percent of our patients are Amish and 20% are from other ethnic backgrounds. We serve all children regardless of ethnic background or ability to pay.

Rare Disorders: The rarity of the medical disorders suffered by our patients is demonstrated by how few children arrive at our door with a diagnosis. Upon their initial visit, only 22% of the children have an existing diagnosis. Currently, we have diagnoses for over 50% of our patients.

Over 30 different genetic and metabolic disorders have been identified in the community. Until we diagnosed four new cases of prolidase deficiency only 40 cases had been reported worldwide. Other rare conditions found in the community are propionic acidemia (1 case in 200,000), Crigler-Najjar Syndrome (200 reported cases), and Cohen Syndrome (100 reported cases worldwide). In the past few months we have found 20+ new cases of Cohen Syndrome. DDC's patient-oriented research centers on diagnosis, treatment and the broad application to the general population.

The significant impact of DDC can be

illustrated through a closer look at five children suffering from prolidase deficiency in the area. The first child died at age three without a diagnosis in 1998. Some estimate that close to \$1 million was spent trying to diagnose and treat this child. The outcome was frustratingly tragic. The second child was diagnosed at the age of two by DDC, the third child was diagnosed at nine months, again by DDC, the fourth child was diagnosed at the age of six months by Rainbow Babies and Children's Hospital of Cleveland. We were able to diagnose the last child at just seven days old. Early diagnosis allows for better treatment, elimination of unnecessary diagnostic tests, and offers relief to the parents. We estimate that being able to diagnose just these four patients will save Northeast Ohio several times over the cost of operating DDC for the first year.

DDC's first year of providing direct medical services has been one of growth and learning. Financially the DDC is sound. Services are expanding and medical findings have been significant. Over the next year we will hire a nurse, dedicate our new facility, increase our patient roster to over 150 children, and continue adding to the understanding and treatment of metabolic and genetic disorders among Northeast Ohio's children.

Dr. Tom Stone, PhD
President—DDC

Dr. Heng Wang, MD, PhD
DDC Medical Director



Another Rare Disease Found in our Community



In our last newsletter, we wrote about prolidase deficiency, a rare genetic disorder we diagnosed in Geauga County. Recently, we identified **Cohen Syndrome**, a disease so rare it affects only about 100 people worldwide. Identifying Cohen Syndrome means that we can now diagnose about 20 of our patients who previously had no diagnosis. We also know that our patients have relatives outside of our area in Holmes County, Ohio, Pennsylvania, Indiana, and Wisconsin, that may have this disease but remain undiagnosed.

This disease is an autosomal recessive disorder. This

means that if both parents are carriers of the recessive gene, each child they have has a 25% chance of having the disease.

Early Findings

Parents who have a child with Cohen Syndrome have told us the same story: newborns with small heads, very low muscle tone or stiffness, and a high-pitched, weak cry, sounding almost like a cat. They also tell of numerous ear infections or pneumonia occurring during the first two years of life along with developmental delays.

General Appearance

Patients with this disease have a smaller head and jaw, big

front teeth, a highly arched roof of the mouth and small and narrow hands and feet. Their joints often overextend and they tend to become overweight before they reach their teenage years. Although these patients tend to have lower IQ's they are generally very social and loving and would like everyone to be their friend.

Prognosis

Although most of the symptoms are not progressive, eye problems such as shortsightedness and retinitis pigmentosa do tend to worsen.

Research Progress

Although we have been able to name this disease, current

treatment for Cohen Syndrome is limited to treatment of the symptoms only. Recently, research performed by a Finnish group published in the June 2003 issue of the *American Journal of Human Genetics* has revealed a COH1 gene mutation associated with this disease. Hopefully, our future research on understanding this disease might someday be able to better help these special children.

If you might have relatives with this disease, or if you would like to learn more, please do not hesitate to contact the DDC office at 440.632.1668.

Thank you to our 2003 PATCHWORK Supporters!

SPECIAL THANKS TO OUR EVENT UNDERWRITERS:

GENERATION SPONSOR: Drs. Vichai & Patra Duangjak • **LEGACY SPONSORS:** National City • Janet Spadora • Susan Patterson • UHHS Geauga Regional Hospital • **FRIENDS:** William & Rebecca Crowley • Florence Klein-Karlin & Larry Karlin • Jim & Nancy Patterson • Paul & Jane Stone • **PATRONS:** Vince & Pat Aveni • Ara & Leslie Bagdasarian • Larry & Nancy Bell • Joe & June Cunningham • H. Joe Davis • Mr. & Mrs. Connor Dodson • Patty Dodson • Dan & Jane Duhl • Gilmour Academy • Bill & Linda Grimm • Christopher Hernan • Margaret A. Hoeler • Gerry & Sally Hornick • Paul & Kathryn Miller • Jim & Kathy Penko • Ron & Barb Pollock • Barbara Reynolds • Harry & Deborah Salzman • Paul & Noelle Schoenhagen • William & Sandra Scott • Marie Seliskar • Edward & Tracie Simon • Les & Linda Vinney

THANK YOU ALSO TO:

To our Board of Directors, Patchwork Committee members and Committee Volunteers for their hard work and dedication as well as to Dave Rennolds and Dee Perry for their job *well done* during the live auction!

OUR SINCERE APPRECIATION TO:

The families of our children with special needs—and especially Nancy Carr, Linda Coblenz, Betty Miller, Carolyn Miller, Frieda Miller, and Ruth Miller • The Bessie Benner Metzenbaum School • Students from Gilmour Academy • Musicians Diane Hein, John Ryan, Heidi Ruby-Kushious, and Ardis Krill • The Center Stage Barbershop Quartet • Robert Eppich of Colonial Wine & Beverage • E.O.U.V. Club & Staff

Thank you to our FACILITY donors and volunteers!

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CHECK OUT OUR WHEELCHAIR LIBRARY

Thanks to Middlefield's **Geauga Vision**, we have been given the unique opportunity to start a wheelchair library.

Geauga Vision's generous donation of 15 adult- and child-size wheelchairs means that any of our patients who may require a wheelchair can come to our facility and "check" one out—just like a library. The only difference is that we don't use a due date and each wheelchair can be returned whenever it is no longer needed. Anyone interested in this program may call our office at 440.632.1668 for more information.



Thank you Geauga Vision for making this program possible!



I will gladly support DDC. Enclosed is my check. My Name _____

Please make the donation in memory/ honor of: Address _____

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Occasion _____

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Make checks payable to:

**DDC Clinic
P.O. Box 845
Middlefield, OH 44062**

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