



# DB STAR

Volume 4 Issue 1  
November, 2002



## 2002 Annual Family Retreat

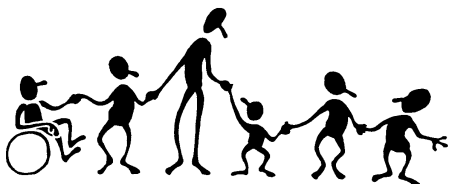


Families from all over Michigan gathered in Flint, Michigan, August 16-18, 2002 to attend the Annual Family Retreat. This year's retreat was sponsored by DB Central and Michigan Association for Deaf-Blind (MADB). The weekend event is an opportunity for families who have children with both vision and hearing impairments to not only meet one another and share stories and experiences, but also to learn from and support one another. Most of all, the Annual Family Retreat is a time to relax and have fun. The seventeen families, along with their children, MADB members, DB Central staff, and many dedicated volunteers, all contributed to the success of this year's retreat.

I would like to personally thank everyone for their time and effort. Without your help, the retreat wouldn't have been nearly as successful.

And lastly, to all the families who participated in this year's retreat, I would like to dedicate this issue of DB STAR. The memories generated from this weekend will last a lifetime. Please share in those memories by reading the following articles written by families who attended.

Patti Nowak  
Family Services Coordinator



**Director**  
Beth Kennedy

**Family Svs.Coordinator**  
Patricia Nowak

**Consultant**  
Jill Gaus

**Admin. Secretary**  
Marianne McJames



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National Family Association  
For Deaf-Blind



*Supporting Persons  
Who Are Deaf-Blind  
and Their Families*

Hi! This is Cynthia Jackson-Glenn, your Regional Director for Region 5. I was very happy to have attended your Family Weekend activities in August and wanted to express that to you. All of you made me feel very comfortable and welcomed, not to mention allowing me to talk on my favorite subject, my daughter, Nafisa. It was a good weekend because the families present really participated in what was going on and developed some positive plans for the future of parents in Michigan with DeafBlind children and advocates alike.

Nafisa is 29 years old and is deaf, blind, and severely mentally retarded as a result of congenital rubella syndrome (CRS). She has taught me and her dad, as parents, how to fight the 'good fight' because she has fought a 'good fight' herself. Finding housing, social, and vocational resources has always been one of the biggest challenges for the deafblind population as they age-out into the community. Through the benefits of the MAPS system, person-centered planning, and strong team advocacy, Nafisa has made a very successful 'transition' into adult life and continues to encourage me to fight the 'good fight' for others who have to face the same hurdles.

As a regional director and member of National Family Association for Deaf-Blind (NFADB), you offered our organization the opportunity to do what we do best: support, encourage, and offer resources to persons with deafblindness and their families. MADB already has strong support from its state project – DB Central—and we can only hope to stand behind their efforts on your behalf. NFADB has been in existence since 1992 and is there to be a voice, nationally, for your concerns, ideas, challenges, and endeavors. I am available as a liaison between you and NFADB and can be reached at:

Phone: 513-681-5136 (voice/tty)

Fax: 513-681-5147

Email: [cyn98onm@fuse.net](mailto:cyn98onm@fuse.net).

You can also reach our organization at 1-800-255-0411, where we are based at Helen Keller National Center in Sands Point, NY. We encourage your membership as a deafblind person, family member, or guardian at the rate of \$15.00 per year. This entitles you to receive our newsletter quarterly, keeping you abreast of the conditions and political climate regarding the deafblind community in our nation, as well as the benefit of a regional contact (myself) as a resource and advocate.

Once again, I thank MADB for being a team to be reckoned with in our efforts as advocates!



## Our First Family Retreat

*By Monique Bonifas*

My name is Monique Bonifas and I'm from Macomb County. My husband, Dave, and I have three children: Kyle 11, Blake 9, and Reid 2. Kyle's deafblindness is due to an unbalanced chromosomal translocation which results in two different syndromes namely, Cri-du-chat and Trisomy 17.

This past August, we were all lucky to attend the Annual Family Retreat in Flint. We were excited about going, but at the same time, a little nervous. This was not only our first retreat with DB Central, but also our first retreat where we brought all our children. We were worried about childcare because our son has other disabilities, including a gastrostomy tube for feeding. DB Central was great in accommodating us by allowing us to bring up a caregiver for my son (my mother), who stayed in the childcare room with all the kids. My husband and I were thrilled to have the onsite childcare, because it allowed us to enjoy the retreat with our children and still be able to participate in a meaningful way.

We learned a great deal from everyone who spoke at the retreat, especially from Cynthia Jackson-Glenn, Regional Director for NFADB. Her presentation made us realize that we needed to get moving on planning our son's future and it's never too soon to start working on a transition plan. She made us laugh, while she shared some most insightful information on the experiences that she had raising her daughter. She introduced us to mapping, a system for futures planning, and shared her daughter's maps with us.

We also really enjoyed the question and answer period with the parent panel and were grateful for the candid answers of the parents who participated. We found ourselves wanting the forum to continue, even though it was time to end.

The pool was a huge hit and a real nice surprise! Since the retreat was relatively close to our home, we chose to drive home in the evening. My nine-year-old was absolutely livid with me regarding this. He wanted to stay overnight with everyone else, something I hadn't expected. I was pleased that he enjoyed himself so much, and promised him that we would stay overnight at the next retreat.

I think the best part for me was being able to meet and talk with the other families and participants in informal little groups. Everyone was very friendly and helpful and we felt like we belonged, which unfortunately isn't a feeling we experience frequently in our everyday lives—but we're working on that.

To everyone at DB Central and MADB, thank you for putting on the retreat. We could see how hard everyone worked and really appreciated all your efforts. We are looking forward to seeing everyone again and meeting new families at next year's retreat!



*Every opportunity to network was used. Here, Monique Bonifas talks with Beth Kennedy (DB Central) and Heather Seidel (childcare volunteer)*



**MICHIGAN SERVICES FOR CHILDREN & YOUTH WHO ARE DEAF-BLIND**

105 Sloan Hall, Central Michigan University, Mount Pleasant, MI 48859  
Toll-Free (V/TTY): (888) 758-0508 or Local (V/TTY): (989) 774-2725 Fax: (989) 774-2553  
E-mail: dbcen@cmich.edu Web Site: www.dbcentral.org

**FAMILY CONSENT FOR SERVICES**

I agree to participate in consultative services for my child, \_\_\_\_\_  
offered through DB Central.

Consultative services are available year round to help address the child's learning and/or family support needs. I understand that services are free and that I will not be charged for services.

Strict confidentiality will be respected at all times, unless permission to exchange information with an identified organization is granted.

This consent is valid for one year from date of signature and may be revoked at anytime.

\_\_\_\_\_  
*Parent Signature*

\_\_\_\_\_  
*Date*

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**CONSENT TO SHARE INFORMATION WITH OTHER ORGANIZATIONS**

The following agencies provide services to individuals who are deaf-blind and their families. Please place your initials beside each agency to which you authorize DB Central to exchange information.

\_\_\_ Child's school (*insert name*): \_\_\_\_\_

\_\_\_ Medical Provider (*insert name*): \_\_\_\_\_

\_\_\_ MI Department of Education, OSE-EIS  
Office of Special Education & Early Intervention Services (517-373-0923)

\_\_\_ MI Department of Career Development - MDCD (866-694-6257)

\_\_\_ MI Family Independence Agency - FIA (517-241-7210)

\_\_\_ MI Commission for the Blind - DB Unit (800-292-4200)

\_\_\_ Community Mental Health / Contact Agency

\_\_\_ Helen Keller National Center (309-755-0067)

\_\_\_ SHI-M=DB, Self Help for Independency in Michigan Equalizing the Deaf-Blind (517-764-6178)

\_\_\_ NFADB, National Family Association for Deaf-Blind (800-255-0411 ext 275)

\_\_\_ MADB, Michigan Association for Deaf-Blind

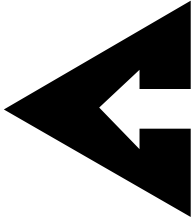
\_\_\_ Other (*insert name*): \_\_\_\_\_

\_\_\_\_\_  
*Parent Signature*

\_\_\_\_\_  
*Date*



## FAMILY CONSENT FORM



**Revised to make referral process quicker—see form on page 4**

- Do you have questions about your child’s education or communication?
- Do you wonder about ways to accommodate your child with a vision or hearing impairment?
- Would you like more information on resources available for your child and/or family?
- Are you interested in meeting other parents of children who are deaf-blind?

**If you answered yes to any of these questions, DB Central can help!  
We can work with your family and your child’s educational team.**

To get DB Central involved, simply fill out the form on page 4 and mail or fax to our office.

If you have questions, please feel free to contact us  
by calling toll-free at 888-758-0508 (V/TTY)

## SEE WHAT M.A.D.B. HAS PLANNED FOR 2002-2003



**M.A.D.B.**

**Michigan  
Association  
for  
Deaf-Blind**

### Goals / Objectives

- **Discuss and adopt a Michigan definition of deaf-blindness**
- Collaborate with DB Central to sponsor a Family Retreat Weekend
- Recruit new members
- Hold one meeting, or mini-family retreat, in a location more accessible to families in the Upper Peninsula of Michigan
- Submit articles for publication in DB Central’s quarterly newsletter, DB STAR
- Plus more.....


 MADB is a network of people who are deaf-blind, parents, family members, professionals, and organizations. If you are interested in learning more or becoming a member, please contact DB Central.



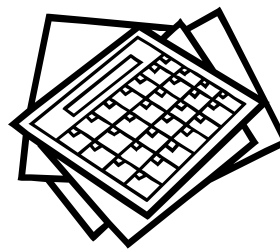
## Volunteering - A Terrific Experience By Doug Kendrick

Curious. Excited. Anxious. Cautious. These are all emotions and feelings that raced through my head on the drive to Flint a few weeks ago. Perhaps more accurately, they are all feelings and emotions I had a few weeks earlier when Patti asked me to volunteer at the Annual Family Retreat in August.

Myself and a friend volunteered to assist with providing daycare at the retreat. Neither one of us has any formal training in working with children with special needs. Basically, what you had, were a couple of 20 something guys that love kids and were willing to help out a friend. I think it's safe to say that both Kerstan and I were a little apprehensive as we arrived for our shift that afternoon. We both just weren't quite sure what to expect... What we discovered was a room full of terrific kids.

Allowing us only a few quick seconds to survey the situation and be introduced to our fellow volunteers, the kids were very excited to show us their remote control helicopter, play with balloons, watch cartoons, and do arts and crafts! The excitement on the faces of the kids in the room made us very comfortable and we jumped right in and tried to help where we could. Before we knew it, the afternoon was almost over and parents were coming in to pick up their children.

Volunteering that day was a terrific experience. I was exposed to children, and family members, very different than what I have become accustomed to and had to take a step outside of my own personal "comfort zone." I walked away that day very proud of what I had done, but much more proud of the brothers, sisters, moms, dads, and other family members that have rallied around their siblings and children. In a society that places so much emphasis on labels, stereotypes, and "disabilities", it was so refreshing to see these kids treated as kids should be—played with, cared for, and loved.



## Upcoming Events

**December 11-14, 2002**

**TASH Conference**

Boston, MA  
[www.tash.org](http://www.tash.org)

**March 15, 2003**

**Helen Keller National Center  
Information Session**

CMU, Mt. Pleasant, MI  
Contact: DB Central (see below)

**March 19-20, 2003**

**Michigan Transition Services  
Association Annual Conference**

Frankenmuth, MI  
[www.mtsa.freesevers.com](http://www.mtsa.freesevers.com)

**July 12-18, 2003**

**AADB-American Association of the  
DeafBlind Conference**

San Diego, CA  
301-495-4403

**July 25-27, 2003**

**CHARGE Syndrome Conference**

Cleveland, OH  
Contact: [conference@chargesyndrome.org](mailto:conference@chargesyndrome.org)

**August 5-10, 2003**

**World Conference on Deafblindness**

Ontario, Canada  
[www.dbconferencecanada.com](http://www.dbconferencecanada.com)

**For more information,  
please contact DB Central  
Phone: 989-774-2725  
Email: [dbcen@cmich.edu](mailto:dbcen@cmich.edu)**

*Do you know of other conferences/  
trainings? Let us know!*

## MY FAMILY HAD A GREAT TIME AT THE FAMILY RETREAT WEEKEND !

*BY: Nancy Hartshorne*

Our family had a great time at the family retreat weekend this year. The facilities were beautiful, the food was great, and the childcare was really fantastic! Of course, there were those bees on the playground...but there seems to be a great rash of yellow jackets everywhere this year!!! My husband enjoyed the speakers, but what is always really great about these weekends is having the chance to get together with other families and share experiences. We saw old friends and met new.

The atmosphere was very relaxed, and it truly was a "retreat" from the everyday hectic life of having a child with special needs. I also cannot say enough about the childcare providers. They made sure my two little boys were entertained, but also were very attentive to and interested in my son, Jacob, who is deaf-blind. I felt very comfortable leaving him in their care. And the facilities at MSB for recreation were fantastic. There was ping-pong, pool, a large screen tv, indoor basketball (like at Chuck E Cheese's), and the childcare providers were doing all kinds of neat crafts with the kids, also. The pool at MSB was really fun. My kids enjoyed putting on all the different sizes of flippers and masks available there. The pool was very warm, and everyone, down to the tiniest child, had a great time.

It is always hard to leave when these things are over. Some of the participants stayed to attend the Michigan Association for Deaf-Blind (MADB) planning meeting. It is always interesting to me to see people from all over the state come together with a common cause, and actually be able to get things done!

Since my first Deaf-Blind family retreat 10 years ago, my family has not missed one since! I would highly recommend this retreat weekend to every family with a child who is deaf-blind in Michigan. Those of us who have attended are now old friends, and we would like to make you our new friends!

*Nancy Hartshorne, mother of Jacob, age 13, who has CHARGE syndrome.*

*Nancy Hartshorne assists  
her son, Jacob, to eat.*

*Eating orally is new for him.*

*Proud brothers Seth (left)  
and Aaron (right) watch*





## Recipe for Terrific DB Central Family Retreat

*Contributed by: Marilyn Park & Joe Jeney*

Combine a warm, sunny August, 2002 weekend (16th-18th) with a comfortable, home like setting on expansive grounds, indoor Olympic size swimming pool, and child play area at the Michigan School for the Deaf and Blind in Flint, Michigan.

### Add:

- 13 loving, committed families
- 4 dedicated DB Central support staff
- 1 dynamic speaker from National Family Association for Deaf-Blind (NFADB)
- a sprinkling of talented interpreters and volunteer caregivers

### Mix in:

- Plenty of time for parents to socialize and relax
- Fun activities for children indoors and out, including an evening swim party for families
- Plenty of great food (cereal, fruit, pizza, chicken, sandwiches, cake, cookies, pop, juice, water & coffee)
- A relaxed setting for parents to listen to and discuss personal experiences with parent-presenter, Cynthia Jackson-Glenn (NFADB) regarding Personal Futures Planning
- An informative panel discussion with parents of adult children with Deaf-Blindness about their successes and challenges working within systems for many years
- A productive meeting of the parent group, Michigan Association for Deaf-Blind (MADB), that includes election of officers, discussion about achievements during past year as well as setting goals for next year and ideas for 2003 retreat.

### Season with:

- Friendly conversation
- Laughs and humor (occasional goofiness)
- Fun loving parents to collaborate on clean-up
- Extra cake and cookies

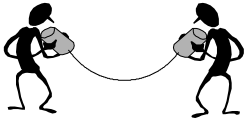
Serve mixture continuously for 48 hours; add additional cake and cookies as needed.

**Doing it all again in 2003 with more participants  
makes the best of chasers.**



## One Parent's Perspective

By Patti Nowak



During a recent telephone conversation with parent, LaKalle Clark, I had the opportunity to ask about her opinions of this year's Family Retreat. Please read what LaKalle shared with me....

Patti: So LaKalle, what did you think about this year's retreat?

LaKalle: It was great! Especially Cynthia Jackson-Glenn. She was excellent when she spoke at the NFADB/NTAC conference in Miami and she was excellent here. I never knew how many opportunities could be out there for my son, TQ, for his future. Hearing Cynthia's story helped me open my eyes that different things could happen compared to my ideas for his future. She gave me a lot of insight about how to get the things I want for him. I loved seeing the pictures of her daughter and learning about the different ways they communicate.

Also, the parent panel was excellent. It was interesting learning what other parents did when their kids were growing up.

It's great to get away from everyday life for a weekend and relax, have fun, and learn some great things, too!

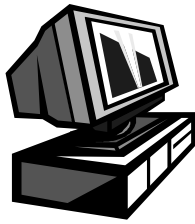
Patti: If you had the chance to speak with other families who did not attend this year's retreat, what would you tell them?

LaKalle: To definitely go to one because every time I go, I learn a lot of things that otherwise I wouldn't have learned. I would want to show families what I have gotten out of it—it has made a difference in my life. Yes, I learn lots of information to help me and TQ, but before, I never knew there were other things out there. At my first retreat, I met other families who were experiencing the same things I was. And I met and saw other kids who also had vision and hearing problems like TQ.



Donald & Gail Newlin participated on a panel consisting of parents with adult children.

Participants with younger children found their insights helpful.



## Have you joined yet? Michigan Deaf-Blind Family Support Listserv

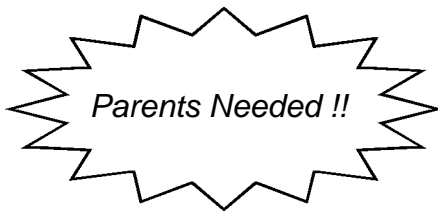
This listserv is designed for families who are impacted by or associated with a child who is deaf-blind. This specific listserv was generated by parents who have communicated their need to connect with other Michigan families. Support will be facilitated through the opportunity to share experiences, gather information, and provide suggestions to one another.

If you are interested in joining this listserv, please post a message to:

MichiganDeaf-BlindFamilySupport-subscribe@yahoogroups.com

or

Contact Patti Nowak @ DB Central via email at: nowak1pm@cmich.edu



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### Michigan Family Resource Guide

A longstanding project for DB Central has been the creation of a comprehensive resource guide for parents in Michigan who have a child with vision and hearing impairments.

The guide will highlight information to address deafblind issues. However, the guide will also contain multiple sources of information to help families support their needs, as identified in previous family needs surveys conducted by DB Central.

We are in the process of completing a "draft" version. It is our goal to invite families to participate in a focus group to review this guide and offer feedback. We want a product that is going to be useful for families, therefore, family feedback is essential. DB Central is planning to provide a stipend to each family (up to 10 families), plus cover additional expenses (mileage, childcare, etc) for those willing to participate in this focus group. Date, time, and location are yet to be determined.

If you are interested in participating, please contact Patti Nowak at DB Central!

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**DB Central has a new fax number: 989-774-1572**  
**Note: We will still receive messages sent to previous number.**

**DB Central  
Michigan Services for Children &  
Youth Who Are Deaf-Blind  
Central Michigan University  
Sloan 105  
Mt. Pleasant, MI 48859**

Non-Profit Organization  
U.S. POSTAGE  
**PAID**  
Mt. Pleasant, MI 48859  
Permit No. 93

**Phone: 989-774-2725 (V/TTY)  
Toll Free: 888-758-0508 (V/TTY)  
Fax: 989-774-1572  
Email: dbcen@cmich.edu  
Website: www.dbcentral.org**



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**New Class !!**

**Interpreting for Deaf-Blind Clients  
Offered by  
Lansing Community College  
Spring, 2003**

**Instructor: Jill Gaus  
Teacher Assistant: Beth Kennedy**

Target audience:

Working interpreters  
2nd year ITP students

For more information contact:

Ashley Oakley @ LCC  
517-483-5329

or

Beth Kennedy  
888-758-0508