



family linkages

NEWSLETTER

A way to connect families of children and youth with special needs in Michigan with information, education and support



ADA American Dental Association*

Give Kids a Smile!

The American Dental Association began the Give Kids A Smile program in 2003 as a way for ADA members to join with others in the community to provide dental services to underserved children. The program initially began as a one-day event in February, but has since grown to local and national events year-round.

Dentists, dental hygienists and other team members volunteer their time, and services, to provide screenings, treatments and education to children throughout the United States. Corporate sponsors also provide expertise and materials to make the program possible. Each year, approximately 450,000 children benefit from more than 1,500 events, all because of the efforts of 40,000 or more annual volunteers.

Michigan has various sites which will be participating in Give Kids a Smile Day (GKAS) throughout February. Fifty five agencies in Michigan have requested materials from the ADA to have programs for GKAS. University of Detroit Mercy School of Dentistry will be providing free oral health care services to more than 150 children from low-income families at UDM's Corktown Campus. The event will provide comprehensive dental care to children ages 4-16. A voucher for free dental care at the UDM Dental Clinic along with an oral health care kit will also be provided. Delta Dental Foundation gave a \$5000 grant for this year's program. Click [here](#) more information.

Learn more about the Give Kids A Smile program, find participating programs or get involved by visiting the Give Kids A Smile website at <http://www.ada.org/givekidsasmile.aspx>

Muscular Dystrophy Association

Duchenne muscular dystrophy (DMD) is a genetic disorder characterized by progressive muscle degeneration and weakness. DMD is caused by an absence of dystrophin, a protein that helps keep muscle cells intact. DMD primarily affects boys, but in rare cases can affect girls.

Symptom onset occurs in early childhood, usually between ages 3 and 5. A preschooler with DMD may seem clumsy and fall often. Parents also may note that children have trouble climbing stairs, getting up from the floor or running. Many children with DMD will begin using a wheelchair sometime between ages 7 and 12. In the teen years, activities involving the arms, legs or trunk may require assistance or mechanical

support. Children with DMD must also have their heart and respiratory function closely monitored.

MDA leads the search for treatments and therapies for DMD. MDA also provides comprehensive supports and expert clinical care for those living with DMD; as well as advocacy work to help individuals and their families the get the answers they need to critical questions about drug development. Research developments occurring in the last decade have led to an increased life expectancy for DMD patients.

For more information about Duchenne Muscular Dystrophy, and the Muscular Dystrophy Association, please visit: www.mda.org or contact your local MDA office in Canton, Okemos, or Saginaw.



FEBRUARY 7-14th is

Congenital Heart Defect Awareness Week



most of us know a family that has been affected by a congenital heart defect (CHD). That's because CHDs are the most common type of birth defect. They affect one out of every 100 newborns. Each year in Michigan, more than 1,700 babies are born with a CHD.

A CHD is caused when the heart or its surrounding vessels do not develop normally during pregnancy. There are many kinds of CHDs, ranging from mild to severe. A baby with a mild CHD may have very few symptoms. But a newborn with a critical congenital heart defect (CCHD) needs treatment right away in order to survive. Anyone can have a child with a CHD. People who have a CHD themselves or have another child with a CHD have a higher chance of having a child with a CHD. It may not be possible to learn the cause of CHD. Talk to your doctor about your chances of having a baby with a CHD. Find out what you can do before or during pregnancy to lower your risk.

Many babies with CHDs have no other problems at birth and seem perfectly healthy. Sometimes a CHD is part of a group of other birth defects, growth, and development problems. A baby's doctor will look to see if the CHD is the only problem. A doctor may recommend that a baby see a geneticist or other specialist to learn whether the CHD has a certain cause or is part of a syndrome. Knowing a cause may be useful in planning how to best care for the baby.

Today, more newborns are surviving and thriving because of early detection and treatment. A new screening test has the potential to find some of the most critical heart defects in newborns. If you are pregnant, be sure to request a pulse oximetry screening test for your newborn. It is a simple test that takes just a few minutes to complete. While this test will not catch every heart defect, it can be helpful in diagnosing undetected critical congenital heart defects (CCHD). Remember, the earlier a CHD is found and treated, the better!

RESOURCES:

MDCH Critical Congenital Heart Defect Screening Pilot Project —

<http://www.michigan.gov/cchd>

Congenital Heart Information Network — <http://tchin.org/index.htm>

Centers for Disease Control and Prevention (CDC) —

<http://www.cdc.gov/ncbddd/heartdefects/>

http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/About-Congenital-Heart-Defects_UCM_001217_Article.jsp



ANNOUNCING THE 11TH ANNUAL
Michigan Fatherhood Conference
A Conference for Practitioners and Male Caretakers Alike!

❁ THE FATHER FACTOR ❁

— fulfilling the father thirst —

Date: Friday, February 22, 2013

Time: Registration - 8:00 am
Conference - 8:45 am - 3:30 pm

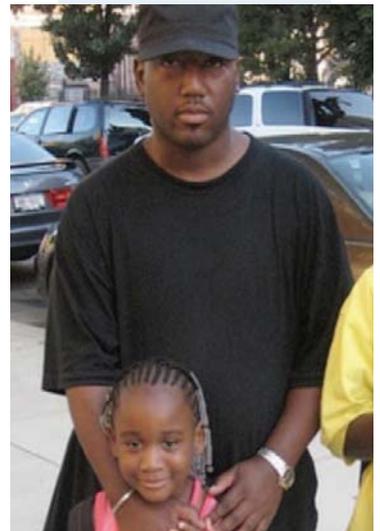
Place: CenterPointe Church
214 Brooks Street
Howell, MI 48843

Contact: Pam Jaymes 734-323-9037

Email: michiganfatherhoodconference@gmail.com

Cost: \$45.00 per person
\$10.00 for CEU's

(Limited scholarships are available for Dads)



NURTURING MEN - Thriving Children
"A Practitioner's Network"



Hide and Seek

By Scott Newport

“Oli, Oli, oxen free!”

Remember that ol’ saying? It was yelled when a player of the game “Hide and Seek” was not able to find all that were hiding. Here is a story where I found something I wasn’t searching for, at least not on the outside.

A couple of weeks back, it snowed all day here in Michigan. It was the first big snow of the year. The weatherman announced we had about 10 inches on the ground when it was all said and done. It was a Sunday, so there was no school or work. For at least that day the harsh, grey conditions of winter would be hidden away and covered by a magical blanket of white powder.

During the course of the day, Noah and I cleared the drive and sidewalk after which we went sledding, with a friend, at our local park. We even took time to help a couple of our neighbors whose cars were stuck. Working and having fun was a great opportunity for a father and son to spend time together. Penni stayed inside and took care of Evan and all his medical needs. Occasionally I would see her bright face peak out the window to see what was going on.

When it was time to come inside Noah and I entered the side door of our home and took off layers of clothes encrusted with hunks of snow. After kicking off our boots we both immediately cornered Penni and told “our” side of the story of who really won the snowball fight and who had gone the farthest on the hill. She smiled graciously as she listened to both of us.

After settling in for the evening, my stomach reminded me that Noah and I had missed lunch. I soon forgot that thought when Penni yelled, “Come and get it!” which is her way of ringing the dinner bell at our home. It was time to eat and I was so delighted to smell the familiar aroma of Penni’s homemade lasagna. I heard the slam of the metal oven door as Penni yelled again for me to come up from the basement. I quickly pointed the remote toward the TV and turned the football game off. After running upstairs, I found myself first in line. Penni piled my plate with a large square of steaming lasagna and a hunk of warm Italian bread.

Noah came running in and was next. As I walked away, I could hear a slice of lasagna hit Noah’s plate. I couldn’t help but feel loved when Noah asked Penni, “Hey mom, why didn’t I get a fork? You put one on dad’s plate and didn’t do it for me. That’s no fair.”

Penni plainly replied, “Look son, you’re a big boy now, you can do some things yourself.”

“Ah... mom,” Noah sighed while walking toward the silverware drawer.

You may not understand the importance of that dialogue. Family life with a chronically ill kid, like Evan, is not always easy. Too often, daily life is marked with an unkind word here or a bit of sarcasm there.

Sometimes it’s hard to love. Many times there isn’t even time for love. Sometimes love is nowhere to be found. There is so much daily stress, so many things to do just to survive. I guess you could say it is like a game of hide and seek. And when you can’t find love that is hidden, you just give up.

But for me, that small gesture was like magic. When my wife put a fork on my plate, it was like seeing her in a sweet dream, blowing me a kiss as she winked. At that moment the love came out of hiding.

It was just a moment in time I had to grasp. It could have been so easily missed, but I caught it. As I sat at the dinner table, eating lasagna and watching the snow fall silently, I thought to myself, “Yeah, she loves Noah and Evan, but I think today she loves me more.”

At least that’s the way I felt.

— Scott (Evan’s dad)



Michigan Family-to-Family Health Information and Education Trainings: Dates/Times/Locations

Caring for a Lifetime; the Beginning, the Middle and the End. An In-depth Look at Pediatric Palliative Care

- March 20, 2013 from 9:30 AM – 1:30 PM at Power Hope and Grace Bible Church, 6495 W. Warren, Detroit, MI 48210

Disability Pride

- March 15, 2013 from 9:00 AM – 3:00 PM at Kalamazoo United Way, 709 South Westnedge Avenue, Kalamazoo, MI 49007

Discipline for Students on IEPs

- February 7, 2013 from 9:00 AM – 3:00 PM at Kalamazoo RESA, Wile Auditorium, 1819 E Milham Avenue, Kalamazoo, MI 49002
- March 12, 2013 from 9:00 AM – 3:00 PM at Power Hope and Grace Bible Church, 6495 W. Warren, Detroit, MI 48210
- March 26, 2012 from 9:00 AM – 3:00 PM at Washtenaw Intermediate School District Vogel Rooms A & B, 1819 South Wagner Road, Ann Arbor, MI 48106 (734) 994-8100

Essential Communication Skills for IEP Team Meetings

- March 20, 2013 from 9:00 AM – 3:00 PM at Eastern Upper Peninsula ISD, 315 Armory Place, Sault Ste. Marie, MI 49783

Tools I Can Use to Help Young Adults Reach Their Hopes and Dreams

- March 28, 2013 from 9:00 AM – 3:00 PM at Clinton County RESA Administrative Building, Redwing Room, 4179 South U.S. 27, St. Johns, MI 48879

Transition Planning? What's That? I Just Want to Help Young Adults Reach Their Hopes and Dreams: Part I

- March 11, 2013 from 9:00 AM – 3:00 PM at Newaygo County RESA's Educational Services Building, Multimedia Room, 4747 W. 48th Street, Fremont, MI 49412
- March 15, 2013 from 9:00 AM – 3:00 PM at COOR ISD, Boardroom, 11051 North Cut Road, Roscommon MI, 48653

Transition Planning? What's That? I Just Want to Help Young Adults Reach Their Hopes and Dreams: Part II

- February 11, 2013 from 9:00 AM – 3:00 PM at Wayne RESA, Annex-Auditorium, 5454 Venoy Road, Wayne, MI 48184

What Every Family and Provider Should Know about Traumatic Brain Injury (TBI)

- March 6, 2013 from 1:00 PM – 4:00 PM at Hope Network, 775 36th Street SE, Wyoming MI 49548

- March 20, 2013 from 9:00 AM – 12:00 PM at Transitions Center—Professional Development Center, 3860 Fashion Square Blvd., Saginaw, MI 48603

To register for Michigan F2FHIEC trainings, visit: <http://www.michiganf2fhiec.com>. Families may call the Family Phone Line at (800) 359-3722.



An Introduction to Positive Behavior Supports (Archived Webinar with Kelly Orginski)

- February 4th, 2013 at 1:00 PM – 3:00 PM or 6:00 PM – 8:00 PM at the Cadillac Wexford Public Library, 411 South Lake Street, Cadillac, MI 49601

Positive Behavior Supports with Aimee Miller, Behavior Specialist

- February 4th, 2013 from 11:00 AM – 1:00 PM at the Grosse Pointe Public Library-Woods Branch, 20680 Mack Avenue, Grosse Pointe Woods, MI 48236

Content of the IEP with Sandee Koski

- February 9, 2013 from 9:00 AM – 2:00 PM at the Warren Community Center 5460 Arden, Warren, MI 48092

WHY can't my child stay in class and out of the principal's office? Behavior and Its Effect on Your Child's Access to Education

Dr. Sally Burton-Hoyle, Eastern Michigan University Autism Collaborative Center & Mark McWilliams, Michigan Protection & Advocacy Service, Inc.

- February 23, 2013 from 10 AM – 3 PM at disAbility Connections, 409 Linden Avenue, Jackson, MI 49203

Re-Thinking Guardianship with Dohn Hoyle, Arc Michigan

- March 6, 2013 from 11:00 AM – 2:30 PM at the Grosse Pointe Public Library-Woods Branch, 20680 Mack Ave, Grosse Pointe Woods, MI 48236

The IEP and Advocacy: What to Know

- March 9th, 2013 9:00 AM – 2:30 PM at the Cross of Christ Lutheran Church, 1100 Lone Pine Road, Bloomfield Hills, MI 48301

To register for Michigan Alliance for Families trainings, visit: www.michiganallianceforfamilies.org/upcoming-events/

