From the Desk of Janine Chittenden BSN, RN  
CSHCS Program Supervisor

Parenting a child with special needs can bring abundant joy, and yet it can also bring challenges beyond measure of untold emotional, physical, social, financial, intellectual, relationship, and self-care stressors.

In addition, parents of special needs children often experience isolation, leaving one to feel alone, over-whelmed, and ill-equipped to face the tremendous challenges of raising a child with special needs.

For many years, your local CSHCS staff sought ways to encourage families. The common thread we heard from parents is that they’d like to talk with parents who share a similar parenting experience, but did not have the time.

Last year, with a grant from the CYSHCS, we started a closed Facebook group for our families and those who care for a child with special healthcare needs. It has over 280 members and continues to grow. There are posts of area resources, questions between families seeking advice, heartwarming stories and more!

We have been given a generous continuance grant and could not be happier that you will be able to continue to share your stories with one another. If you have not joined, please consider. If you have suggestions, we want to hear from you. Find the group on Facebook by searching for Special Families’ Corner. Then click on ‘Join Group’ to request to be added as a member.

Wishing you and your child happy holidays and improved health,

Janine Chittenden, CSHCS Program Coordinator

www.michigan.gov/cshcs  

www.miottawa.org/CSHCS

In This Special Kid’s Corner:

- CSHCS Contacts
- Parent’s Corner
- CSHCS Policy Updates
- Facebook Group
- MI ABLE Accounts
- Compassionate Heart Ministry
- Safe Medication Disposal
- Free Fire Alarms
- Local Epilepsy Presentation
- Children’s Healing Center
- Community Resources
- Holiday Tips for Special Needs
- Kid’s Holiday Activity

CSHCS Values Your Feedback!!!

Do you have a suggestion for improving CSHCS services?
Do you have an idea that would help us meet the Needs of special families in Ottawa County?

We would love to have your comments or suggestions!
Please sent them to Amy Fontaine, our parent consultant: afontaine@miottawa.org

‘Special Kid’s Corner’ is written by CSHCS staff, edited by Amy Fontaine, & made possible with generous funding from: The Family Center for Children and Youth with Special Health Care Needs Phone Line: 1-800-359-3722
Ottawa County CSHCS Contact Info:

Brenda Kempf, Program Representative
Phone: 616-393-4445
Email: bkempf@miottawa.org
Contact Brenda for:
- annual renewals
- adding providers
- financial concerns and significant income changes
- billing issues
- travel and lodging requests
- scheduling a nurse appointment

Irene Atwood, Support Staff
Phone: 616-393-4439
Email: iatwood@miottawa.org
Contact Irene for:
- changes in name, address, phone, e-mail
- insurance changes

Kelsey DeMull BSN, RN, MPH
Phone: 616-393-4442
Email: kdemull@miottawa.org
Kelsey is your nurse if you live in:
- Allendale, Holland, Zeeland, Jenison
- or you have a Grand Rapids zip code.

Leslie Ver Duin BSN, RN
Phone: 616-393-4444
Email: lverduin@miottawa.org
Leslie is your nurse if you live in:
- Grand Haven, Spring Lake,
- Coopersville, Hudsonville, West Olive,
- or other outlying areas.

Contact Your CSHCS Program Nurse for:
- Plans of Care
- medical questions
- questions about coverage
- adding a new diagnosis
- adding a new specialist

Janine Chittenden BSN, RN, Program Supervisor
Phone: 616-393-4436
Email: jchittenden@miottawa.org
Contact Janine for:
- Concerns or questions that other staff have not been able to answer

CSHCS Program Fax: 616-393-4435

The Family Center for Children and Youth with Special Health Care Needs

The Family Center is the parent-directed center within Children’s Special Health Care Services (CSHCS)

The Family Center offers emotional support, information, and connections to community-based resources:

- to any family of children and youth with special health care needs
- who have, or are at an increased risk for physical, developmental, behavioral or emotional conditions.

Children do NOT need to be enrolled in CSHCS to receive services from the Family Center.

The Family Center Phone Line:
1-800-359-3722

The Family Support Network
For parent-to-parent support
1-800-359-3722

State of Michigan CSHCS website:
www.michigan.gov/cshcs

CSHCS Online payment site:
God’s Story

My name is Deb Bosch. First, I am a child of the King. Second, I am the wife of an amazing man. Third, I am of the mom of 4 (and now 7 amazing people that call me MOM). Fourth, I am a nurse.

About 21 years ago, our lives took an amazing turn. Our family was doing our family thing and life was clicking along. On October 14, 1995 we were blessed with our fourth child. However, something major was not right. Tim was born with 12 fractured bones and he had another 12 bones that had fractured while in the womb. Those fractures were partially healed. We quickly got the diagnosis on Osteogenesis Imperfecta, or brittle bones.

Unexpected turns in life are hard. And, as most of you can relate, you have to navigate this strange journey with a husband and other children too!!! As a family, it was like we got shoved off the main highway. We didn’t even know really where to go. We had no map. We could see our friends and family on the main highway but we could no longer get on that road. It was hard!

Tim was given a prognosis of about a year. He was fracturing bones every couple of weeks. We very quickly learned to carry Tim on a pillow. Just our finger pressure could break his bones. He would get toes caught in pajamas and break legs. He would cough and break ribs. He would roll on his side and break arms. It was like having an amazing crystal pitcher that you wanted to put on the highest shelf in the dining room, but you couldn’t—you had to use the pitcher every day for Kool Aid!!!

Life was a challenge. Even as a nurse, with lots of friends in the medical field, it was hard learning how to navigate the medical system, pay bills, and keep working so I could have medical insurance. We needed special assistance for Tim to attend school. We needed help to get him to and from school. We needed help to keep Tim on top of his classes when so much was missed with so many fractures. We needed special clothes to fit around all the different casts.

Today, God is good! He always is! Tim has had over 500 fractures and 50 major surgeries. He is an amazing young man! He is currently a junior at Calvin in the engineering program. One smart kid! “My disease is not a disability but an ability that God has used over the course of my life to bless many people and bring glory to God.” Tim has been the speaker at schools, colleges, and businesses over the years.

Don’t get me wrong, life is still a challenge. But we live life on our knees! My kids are now getting married, so we have three new kids. My daughters are both nurses. My son helps mentor special needs kids. Tim keeps advocating for people who are physically challenged.

Life. We have no control over most circumstances that come into our lives. But, we do have control over how we react. We can chose to become bitter and mad. Or we can chose to stand up to the challenge. Become better people. Learn from what God has placed in our paths. We are so blessed!

We have so much to be thankful for!! I would love for my son to never have pain again. I would love for him to be able to run and jump like his friends. But, we would not be the people we are today if we had stayed on that main highway. Hopefully, we are better people for the journey. Oh, and did I say we are so thankful!!!!
Our group was created exclusively for parents and caregivers who are raising children and youth with special needs. Join us for:

- Parent-to-parent support
- Grant opportunities
- Community and online resources
- News that affects the special needs community—including opportunities for advocacy
- Local and online events for special families

Joining is easy. Just search Facebook for **Special Families’ Corner** and ask to join by clicking on “Join Group.”

Over 280 special needs parents have joined us, we hope you will too!

**Special Families’ Corner** is a closed group, so posts are seen only by members.

If you have any questions, email or FB message our group administrator, Amy Fontaine: afontaine@miottawa.org.

**Existing Group Members, if you aren’t seeing posts:**

- Adjust the settings in your group list to ‘See all posts’.
- Like or Comment on a few posts, so Facebook’s ‘secret-sauce’ knows that you want to see our group posts.

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**Important CSHCS Program Changes and Updates**

**You may notice an ICD code change on your next Client Eligibility Notice (CEN).**

Every diagnosis has an ICD diagnosis code, and these codes are updated annually.

- A few of the ICD codes that are CSHCS-qualifying codes were updated this year.
- September 30, 2016 was the effective date for the replacement codes. Note: In example, ICD code Q252 (for Atresia of Aorta) was replaced with code Q259 on 9-30-16.

**Two new CSHCS-qualifying conditions were added to our client eligibility list, effective October 1, 2016.**

If you have a child with either of these conditions, please let us know:

1. Ehlers-Danlos (ICD code Q796)
2. Zika Virus Disease (ICD code A925). Note: CSHCS will cover Zika infection of the child on a case-by-case basis, dependent on the symptoms, severity, and treatment plan.

**CSHCS Lodging and Mileage reimbursement rates have changed, effective October 1, 2016.**

- Lodging reimbursement has increased to $41.25 per night.
- Mileage reimbursement rates were decreased from 23 cents per mile to 19 cents per mile.
  Note: This change is consistent with the current Medicaid reimbursement rate.

**CSHCS no longer deducts a step parent’s income from the household income amount.**

- You must report your household income as it appears on your tax forms, without deducting the step parent’s income.

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**Special Families’ Corner Facebook Group**

Our group was created exclusively for parents and caregivers who are raising children and youth with special needs.

**Join us for:** parent-to-parent support, grant opportunities, community and online resources, news that affects the special needs community—including opportunities for advocacy—local and online events for special families, and much more!

Joining is easy....just search Facebook for **Special Families’ Corner** and ask to join by clicking on “Join Group”.

Over 280 special needs parents have joined us, we hope you will too!

**Special Families’ Corner** is a closed group, so posts are seen only by members.

If you have any questions, email or FB message our group administrator, Amy Fontaine: afontaine@miottawa.org.

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This group is made possible by generous funding from **The Family Center** for Children and Youth with Special Health Care Needs, the parent-directed center within CSHCS.

**The Family Center phone Line:** 1-800-359-3722 is open to all parents and caregivers of special needs children, regardless of CSHCS enrollment.
Michigan’s Achieving a Better Life Experience (MI ABLE 529 Program) Enrollment is Now Open!

Michigan’s Achieving a Better Life Experience (MI ABLE 529 Program) was signed into law by Lt. Governor Brian Calley in October 2015.

Michigan’s Achieving a Better Life Experience (MI ABLE) program is part of a national program created to enable families and persons with disabilities to save funds in order to maintain health, independence and quality of life; and to provide secure funding for qualified disability related expenses.

The significance of the program is that it allows qualified individuals to save for disability related expenses in a tax-exempt MiABLE savings account, without losing eligibility for public benefits, such as Medicaid, SSI, and SNAP. Prior to MI ABLE, individuals lost eligibility for these benefits if they had more than $2,000 in savings or other significant assets.

The MI ABLE program allows maximum contributions of up to $14,000 annually (total from all sources—family, friends, and beneficiary), and a $500,000 lifetime maximum contribution for all 529 accounts combined.

Note: Only the first $100,000 in MI ABLE savings is exempt for SSI eligibility purposes, so SSI would no longer pay a monthly cash benefit, but Medicaid benefits will continue.

To qualify to open a MI ABLE Savings Account, individuals must have significant disabilities, with onset occurring prior to the age of 26. Individuals over the age of 26 must provide documentation that the onset of the disability occurred prior to age 26.

To open a MI ABLE Savings Account, or to learn more, go to: https://www.miable.org/

To hear a recorded webinar from the ABLE National Resource Center: Understanding the investment side of owning and maintaining an ABLE account: https://www.youtube.com/watch?v=7rjCcoG8i50&feature=share

Compassionate Heart Ministry
A few words from Donna Bunce, Founder and Director of CHM:

Dear Fellow Special Needs Families,

I am excited to share all the wonderful things that are happening at Compassionate Heart! It’s hard to know where to start, as 2016 was a BIG year for us! Moving into our beautiful, new 20,500 square foot facility was a blessing beyond measure! Never in my life would I imagine that we would be in our very own facility…never!

Compassionate Heart originally opened its doors in January 2007, at City on a Hill in Zeeland. We hoped to provide a FUN, safe, inclusive, Christ-centered, drop in center for about 25 special needs families looking for an after-school program for their teen; a place to make friends and develop friendships with their peers.

As the Founder and Director, I know first-hand what the loneliness, hopelessness, and pain feels like for parents. I know what it feels like to watch your child be left out of friendships and social/recreational groups because of their special needs. I know the sadness that my son feels when people tease him because he speaks differently or acts socially awkward, even inappropriate (at times) because of his autism.

Compassionate Heart is different. It is a place where people with disabilities will feel safe, valued and accepted. It is a place where people can participate in fun, community and social opportunities like parades, sporting events, and Art Prize! Compassionate Heart provides the place where peer mentors and volunteers gather and come alongside these young people with mild to moderate disabilities and help make life full and fun.

The ministry is solely funded by generous individuals, corporations, churches and local grants. We receive no federal funds to support this program. Individuals pay a small fee of $7.00 per visit, and if they wish to purchase dinner, there is an additional $5.00 fee.

Our program days are offered according to age group, so please visit our website for details. We are open:

Mondays, Tuesdays, & Thursdays: 3:00pm--8:00pm.
Wednesdays: 9:00am--5:00pm

If you are interested in having your son or daughter participate in this program, please contact Lee DeWitt, our participant coordinator at: 616-834-0501 Ext. 200 for an interview. He will be happy to meet you and answer any of your questions.

We hope to see you sometime….Merry Christmas,

Donna Bunce, Executive Director

Compassionate Heart Ministry
404 Centerstone Road Zeeland, MI 49464
616-834-0501
http://www.compheart.org/
Our Special Needs Children are often prescribed a multitude of medications, dosages are changed, meds are added and subtracted... and all this means our medicine storage is usually A LOT fuller than most.

However, keeping expired, unused, or no-longer-needed medications poses a threat to the safety of our children. Each year more than 71,000 children are seen in emergency rooms for unintentional ingestion or overdoses of prescription or over-the-counter drugs.

Keep your family safe by following these Steps for Safe Medication Disposal:

1. Do Not Flush prescription or over-the-counter medicines.
2. Keep medications in original containers.
3. Leave the label on, to show the medication name.
4. Black out all personal information.

5. Decide where to take your medications for safe disposal using the information below:

Most Pharmacies Will Accept:

- Non-controlled Prescription medications
- Over the counter medications
- Medication samples
- Medications for pets
- Vitamins
- Medicated ointments/lotions
- Liquid medicine in glass or leak proof containers (up to 12oz)

Use Law Enforcement Drop Boxes for

- Narcotic pain killers
- Prescribed controlled medications

For a list of Pharmacies and Law Enforcement Drop Boxes near you, go to: www.wmtakebackmeds.org

The Ottawa County Sharps Program offers free home-use medical sharps containers to residents. Stop by any Health Department branch to pick up a container and bring it back when it’s full to receive a new one. Only Ottawa County Health Department issued containers will be accepted.

For more information, contact:
Ottawa County Medicine Disposal or Household Hazardous Waste 616-494-5569

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SAFE MEDICATION DISPOSAL

FREE FIRE ALARMS

Over 80 lives have been saved due to the Free Fire Alarm Program

This life-saving program is a joint effort between local fire departments and the Ottawa County American Red Cross.

The fire alarms are FREE and installed by American Red Cross volunteers, community partners, and/or fire fighters.

The alarms are 10-year life, battery operated alarms (no hard-wired alarms available).

To get your FREE Fire Alarms installed:

Contact Sandy Oudemolen, at the American Red Cross office: 616-396-6545.

Provide the following:

1. The name of the homeowner or renter.
2. The property address and telephone number.
3. The number of bedrooms in the home (fire alarms will be installed in each bedroom).
4. If anyone with a disability lives in the home. Sandy will notify the local fire department about the special need in case of a fire.

5. If there are deaf person(s) living in the home. A special alarm can be ordered. This special alarm shakes the bed and emits an extremely bright light to wake the individual.

Sandy will contact you to set up a date and time for installation. A minimum of two people, including an American Red Cross volunteer, will be in attendance at the installation.

A service acknowledgement is signed by the person(s) living in the home following the installation of the alarms.
Children’s Special Health Care Services of Ottawa County Invites you to attend

The Epilepsy Foundation of Michigan’s ‘Living with Childhood Epilepsy’

A presentation by:
Cindy Hanford, RN
Education and Advocacy Expert

January 17, 2016 Noon — 2:00pm
Ottawa County Department of Public Health
12251 James Street, Holland, MI

The event is free, and a light lunch will be served. Reservations are required, as spaces are limited.

To register: send an email with your name, contact information and number of persons attending to: Amy Fontaine: afontaine@miottawa.org

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Loutit District Library
407 Columbus Ave. Grand Haven

Special Needs Storytime
Tuesday, January 31, 2017
6:30 — 7:00 p.m.
Enjoy a fun story time specially designed for children who have special needs.

Join children’s librarian and former special educator, Susan Trittin, for this fun family event. She’ll provide a tailor-made story-time experience for the children who attend, including the opportunity for movement and to learn about the fun activities and materials the library offers in addition to books.

Her goal in creating this event, says Susan, “is for families and students to know that ALL children are welcome at Loutit Library”.

Susan hopes to provide special needs children with a fun story-time experience and time for families to bond and to try something new in a safe and accepting environment.

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Dolly Parton’s Imagination Library
Audio & Braille Books

Dolly Parton's Imagination Library (DPII) has partnered with American Printing House for the Blind, Inc. (APH) to make many of the wonderful books in her program, available in braille and audio format so that young blind and visually impaired children can also benefit from these wonderful children's books.

Thanks to a collaborative effort between DPII, APH and Penguin Group, USA, an ever expanding collection of titles will be available as free downloadable children's audio books and for those who prefer, there will be many titles available in braille from APH. These will be offered free-of-charge to eligible families and may be purchased at a low cost by all others.

Dolly Parton’s Imagination library
http://usa.imaginationlibrary.com/

Tri-Cities Imagination Library
616-402-0961
Sick kids now have a safe place to play thanks to the Children’s Healing Center

Located in Grand Rapids, the Children’s healing Center is the nation’s first, year-round Recreation Center that offers a safe, clean and interactive place for children with weak immune systems and their siblings.

Through free-play or scheduled classes, families can connect and break through the feelings of isolation that serious illness can cause. Members receive a short health screening before they enter the virtually germ-free play area, which uses state-of-the-art technology and hospital-grade design.

The Center’s 7,000-square-foot facility has four main zones:
Exploratory Play, Art and Learning, Active fitness, & Tech.

With activities for everyone, here are four member favorites:

**Painting Classes**: Picasso or Michelangelo? Kids can unleash their creativity through the various art classes held at The Center. Art can be therapeutic for kids going through a difficult time—as witnessed by the dozens of paintings from kids at the CHC.

**Play Date Wall**: Kids can take over their environment by using colorful magnetized decals and a special white-board to create different images. Flowers and pencils to books, animals and abstract shapes – no matter what is in a child’s mind, they can express it on this interactive wall.

**Obstacle course**: We regularly transform our active fitness play space into an obstacle course where kids can test their skills and improve their speed as they navigate a child-sized course. Obstacles range from riding scooters through a maze of cones to climbing over foam mats to slam dunking a ball. Rewards come in the form of healthy treats.

**Pretend Store**: Commerce comes to life as kids channel their inner entrepreneur with the Center's handcrafted play storefront. Whether they are selling tomatoes or widgets, kids get to replicate real life in this fun area that promotes imagination and social interaction.

If your family, or a family you know, would benefit from an oasis like The Children’s Healing Center, please fill out our referral form: http://www.childrenshealingcenter.org/membership/refer-a-family

For more information or to take a tour, call: (616) 426-8366.
Find them on the web at: http://www.childrenshealingcenter.org/
Or on Facebook too: https://www.facebook.com/childrenshealingcenter

**Holiday Break Camps will take place**
December 26th—28th, and on January 2nd

See the CHC calendar link for details:
http://www.childrenshealingcenter.org/calendar/
Holiday Tips
For Special Families

The holidays seem to magnify the beauty of life and the abundant love we have for our precious children. To help with the added stress that seems to come along as well, we found a few tips that we hope will help keep the merry in your holidays.

Try to keep a thread of normalcy:
Special needs children often feel more secure and less anxious when life follows a predictable routine.

Prepare your child for special events with social stories or books:
Create an original story to suite your unique situation, or access social stories designed for specific situations here:

Manage social activities for success:
• Consider sending a letter to family members who love your child, but may not know him or her well, ahead of a family gathering (it could even be written “from” your child). This will help them get to know your child and how they can help make the time with your child a success.
• Create a list of gift suggestions for family who may want to buy your child something special. This will help to make sure is developmentally appropriate and that it more likely to be well-received.
• If your child is easily overwhelmed by crowds or has sensory processing issues, bring along a bag with some comfort and sensory items. Here are some great suggestions for what to bring along:
• Consider bringing a babysitter or helper to a special event to help keep your child happy and safe. It goes without saying that even the best of parents can get momentarily distracted in social situations.
• If your child has food allergies, bring food that you know is safe for your child, to avoid the risk of exposure or cross-contamination. Have an emergency plan in place, and make sure you have immediate access to all life-saving medications.

Find fun holiday activities geared toward special needs children:
There are more options available than ever before, such as movie theaters with “sensory” showings (lights up, sounds down), pre-scheduled Santa visits to reduce wait times and avoid crowds, special needs swim times, adaptive sleigh rides, and more. If you search online, or join our Special Families’ Corner Facebook group, you will find some wonderful holiday happenings for special needs families.

Create new traditions and find adaptations that work for your special family:
Letting go of the idea of a picture perfect Christmas can be freeing! With a little inspiration, you can start new traditions that are just right for your special family.

May the blessings of life be magnified for all of our special families this holiday season!
~Your Children’s Special Health Care Team

January 2017 IEP Webinar Series

Webinars take place each Wednesday in January from 12pm—1pm

January 4   Skills for Effective Parent Advocacy
January 11  Importance of the PLAAFP Statement
January 18  Goals and Objectives
January 25  Supports and Services, including Accommodations and Modifications

Webinar Series Registration:
https://attendee.gotowebinar.com/register/4800973921387321345

Space is limited, so register online today. A single registration signs you up for all four webinars. You’ll receive a confirmation email with directions for accessing the webinars.
For more gingerbread fun:

Snuggle up with Jan Brett’s newest book, “Gingerbread Christmas”

Build a gingerbread house at:  http://www.janbrett.com/trim_a_jan_brett_gingerbread_baby_house.htm

Play online gingerbread man games:  http://www.topmarks.co.uk/learning-to-count/gingerbread-man-game

Listen to a traditional gingerbread story at: