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

Everything good happens between June and August. Is this true for you too? It’s my favorite time of the year. Our days are long, warm, and it seems powdered gold shines across the garden. At the beach the sunset bursts with color, along the drive farmer’s fruit stands bear raspberries, blueberries, and peaches, and the kids are thrilled to be out of school and playing for hours at a time. We get to shed the skin of our homes to join mother’s nature. Our windows are open, the bees and monarch butterflies search our hanging baskets, and one might find time for a round of golf, a family bike ride, or an evening in the yard waiting for fire flies and stars to strut their stuff.

Whether your idea of a good time is a summer read, the kids eating watermelon, or getting your toes in the sand, I hope your schedule of doctor appointments and therapies has lessened and that your child is enjoying the fresh air of summer. May you enjoy August as if you are on pause on top of a Ferris wheel. You have made it through a lot - the crazy busy school year, the frantic holiday season, and even the spring showers.

Without hesitancy, I hope you do something today that brings a heart-warming smile to your face.

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

www.michigan.gov/cshcs

July 2017

SPECIAL KID’S CORNER
News and Updates from Ottawa County CSHCS

In This Special Kid’s Corner:

Page 2 CSHCS Team Contact Information & Who to Call For What
Page 3 Getting the Most from your CSHCS Enrollment
Page 3 The Family Center
Page 4 Parent’s Corner: Guardianship X’s 3
Page 5 CSHCS Transition Assistance & Resources
Page 6 Preventing Tick-Borne Illness & Steps for Tick Removal
Page 7 Family Leadership Network — seeking new leaders Apply by July 28!
Page 7 Sibshops Introduction & Training Aug 25 & 26
Page 8 Family Hope Foundation
Page 8 The Children with Special Needs Fund
Page 8 The Brainy Day 5K 10K Walk/Run
Page 9 Special Families Corner FB Group
Page 10 Kids Corner Activity & Summer Fun Idea Links

CSHCS Values Your Feedback!!!
Do you have a suggestion for improving CSHCS services? An idea that would help CSHCS help special needs families? We would love your input! Please contact Amy Fontaine, our parent consultant: afontaine@miottawa.org

‘Special Kid’s Corner’ is written by the your CSHCS staff and edited by Amy Fontaine, parent consultant. This edition was made possible by generous funding from The Family Center for Children and Youth with Special Health Care Needs.
The Ottawa County CSHCS Team

Irene Atwood, Support Staff
616-393-4439
iatwood@miottawa.org

Brenda Kempf, Representative
616-393-4445
bkempf@miottawa.org

Janine Chittenden BSN RN, Supervisor
616-393-4436
jchittenden@miottawa.org

CSHCS Program Fax: 616-393-4435

Leslie Ver Duin BSN RN, Nurse
616-393-4444
iverduin@miottawa.org

Grand Haven, Spring Lake, West Olive, Coopersville, Hudsonville

Kelsey DeMull BSN RN MPH, Nurse
616-393-4442
kdemull@miottawa.org

Holland, Zeeland, Allendale, Jenison

A CSHCS Quick Guide: Who can best help with what

Contact Irene for:
- Insurance changes
- Changes in address, phone, email address or name

Contact Brenda for:
- Billing issues and coordinating insurance benefits
- Income change (significant) or other financial concerns
- Adding specialty providers
- Annual CSHCS renewals
- Travel and lodging requests
- Scheduling a nurse appointment

Contact your* nurse for:
- Plans of Care
- Medical questions
- Coverage questions
- Adding a new diagnosis or a new specialist

* Nurse coverage areas are listed above

Contact Janine with concerns or questions that other CSHCS staff have not been able to answer

State of Michigan CSHCS website: www.michigan.gov/cshcs
The Family Center is the parent-directed center within CSHCS and The Michigan Department of Health and Human Services.

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 may be at increased risk for physical, developmental, behavioral or emotional conditions.

**NOTE:** Children do NOT need to be enrolled in CSHCS to receive services from The Family Center.

**CSHCS can help you:**
- Coordinate insurance benefits
- Resolve billing issues
- Arrange private duty nursing and respite care
- Connect with community agencies and resources
- Locate financial resources, such as scholarships and grants
- Apply to the Children with Special Needs (CSN) Fund
- Connect with other special needs families

**CSHCS nurses can help:**
- Locate and provide information about specialty providers, such as doctors, hospitals and clinics
- Coordinate services from multiple providers and agencies
- With the transition to adulthood
- Develop a Plan of Care (POC) to set goals for your child’s health care and your family’s well-being

---

The Family Support Network for parent-to-parent support

**Phone Line**

1-800-359-3722

Monday thru Friday
8am — 5pm

cshcsfc@michigan.gov

---

CSHCS can help you:

- Coordinate insurance benefits
- Resolve billing issues
- Arrange private duty nursing and respite care
- Connect with community agencies and resources
- Locate financial resources, such as scholarships and grants
- Apply to the Children with Special Needs (CSN) Fund
- Connect with other special needs families

CSHCS nurses can help:

- Locate and provide information about specialty providers, such as doctors, hospitals and clinics
- Coordinate services from multiple providers and agencies
- With the transition to adulthood
- Develop a Plan of Care (POC) to set goals for your child’s health care and your family’s well-being

---

CSHCS can help you:

- Coordinate insurance benefits
- Resolve billing issues
- Arrange private duty nursing and respite care
- Connect with community agencies and resources
- Locate financial resources, such as scholarships and grants
- Apply to the Children with Special Needs (CSN) Fund
- Connect with other special needs families

CSHCS nurses can help:

- Locate and provide information about specialty providers, such as doctors, hospitals and clinics
- Coordinate services from multiple providers and agencies
- With the transition to adulthood
- Develop a Plan of Care (POC) to set goals for your child’s health care and your family’s well-being

---

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 may be at increased risk for physical, developmental, behavioral or emotional conditions.

**NOTE:** Children do NOT need to be enrolled in CSHCS to receive services from The Family Center.

---

The Family Support Network for parent-to-parent support

**Phone Line**

1-800-359-3722

Monday thru Friday
8am — 5pm

cshcsfc@michigan.gov
Guardianship Times Three

Wow, 18 years old! My triplets were born very early and so very tiny. They have made great strides since those early fragile days, yet each will need continued support, in varying degrees, during adulthood. Though there are options to consider, guardianship was the best fit for us. I hope that sharing what I discovered on our guardianship journey will help you prepare if you find yourself on a similar path.

Psychological testing—for intelligence and adaptive abilities—is a requirement for ALL guardianships in Michigan; it must be done within a year prior to applying:

- Resources for psychological testing are posted on the Ottawa County Probate Court website (see link below). You could also ask for recommendations in our ‘Special Families’ Corner’ Facebook group.
- Testing is expensive—$600 per child in our case. This fee covered the testing, all reports, and testifying at our guardianship hearing.
- We tested in my home, for an hour each child. The psychologist was very positive with each of my kiddos, and was able to make accommodations for my non-verbal daughter.
- During the testing, I completed an inventory on development and daily living skills for each child.
- The psychologist helped me fill out the court’s guardianship forms—so print them before hand (see link below).
- Our testing reports arrived within two weeks.

Testing results guide the type of guardianship:
- **Partial Guardianship**—temporary (5 years)
- **Full Guardianship**—Plenary/permanent
  Note: Full guardianship includes help with decision making in ALL life areas; Partial guardianship does not include social decisions.

File your completed paperwork with the Ottawa County Probate Court:
- You must include your psychological testing report with your “Petition for Appointment of Guardian”.
- The court will give you a docket number and hearing date—usually in about 3-4 weeks.

File ‘Proof of Service’ with the court:
- **Do this after** you’ve sent copies of the “Petition for Guardianship” and “Notice of Hearing” to everyone with an interest in the guardianship—including your child, the alternative guardian, agencies, attorneys, non-custodial parent, etc.

The court appoints a lawyer for your child:
- This is done at no cost to you or your child.
- I received written communication from their attorney, and each child met with their lawyer for a few minutes prior to the hearing.

Attend the guardianship hearing with your child:
- **Your child must attend** the hearing with you (ipads or other distractions were allowed).
- To get into the court building, you need to go through the metal detector and show the contents of purses, etc.
- The psychologist testifies in the witness box. We sat in chairs across from the judge’s bench.
- The judge might ask you a question or two that you answer from your seat (he asked if I had anything to add to what the psychologist said).
- This whole process took about 15 minutes per child, and we waited in the lobby for our completed guardianship paperwork.

Make copies to distribute to all interested parties, such as doctors, schools, agencies, etc.
In your CSHCS journey, we want to help and support your youth in their transition to adulthood. We all want our children to become as independent, self-determined, and as healthy as possible. This is a process that happens over time and it looks different for every person.

Here are some things to consider:

- How much does your child know about their diagnosis/disability and how to manage it?
- Does your child schedule their own appointments?
- Is he or she ready to take this on?
- How long will your pediatric specialist continue to care for them?
- What are the insurance and transportation options down the road?
- What is next for education or career planning?

CSHCS has a checklist that will help your child and you gauge where you each stand on adulthood transition readiness. Having your child complete it should assist clarifying “next steps” and preferences. A clear and concise plan, with goals, strategies, and resources will track your progress. This plan lays a clear path for your youth to achieve optimal independence and success as they enter adulthood.

If your child is 14 or older, ask your CSHCS nurse to share the Transition Readiness Assessment. You can also find it at the first link below. You’ll be so glad you did! Should you wait, your CSHCS RN may soon be asking your child to complete it. Becoming an adult can be both exciting and scary, but with a plan, the transition can go much smoother.

Online Transition Resources:

Links are live—except for the first, you’ll have to copy and past it

MDHHS: Transition Tools for Youth, their Families, and Health Care Professionals
http://www.michigan.gov/mdhhs/0,5885,7-339-71547_35698-135030--,00.html

Transition Planning: A Guide for Young Adults and Family:

GVSU Start Project Transition Resources:
https://www.gvsu.edu/autismcenter/transition-resources-138.htm

Health Care Transition:
http://www.gottransition.org/

Education Transition:
http://www.michiganallianceforfamilies.org/education/transition/
http://www.wrightslaw.com/info/trans.index.htm
www.thinkcollege.net

Transition Videos:

“Self-Determination Means”
https://vimeo.com/89515085

“Importance of Knowing Your Disability”
https://vimeo.com/100993221
Preventing tick-borne illness

West Michigan is a hot spot for fun in the sun, but did you know that Ottawa County is also a known hot spot for the black-legged tick (deer tick) that can transmit Lyme disease and other tick-borne illness.

Prevent Tick bite:

Avoid contact with ticks:
- Walk in the center of trails
- Avoid wooded or brushy areas with high grass or dead leaves

Create tick-safe zones:
- Keep vegetation away from patios and play areas
- Clear leaves, tall grasses and brush from around your home
- Create a border of wood chips or gravel between your lawn and wooded areas
- Use a chemical control agent

Use insect repellent for people and pets:
- Apply DEET (20-30%) or Picaridin on exposed skin
- Treat clothing and gear (boots, pants, socks, tents) with products containing 0.5% Permethrin*
  *Do NOT apply Permethrin directly on skin
- Always follow manufacturer’s instructions when applying repellents

After spending time outdoors:
- Do a daily full-body tick check on all family members and pets (see details at top right)
- Bathe or shower (preferably within two hours)
- Examine gear and pets to prevent ticks from being carried into your home
- Dry clothes—before washing. Dry on high heat for at least 6 minutes to kill ticks (from a new CDC study), or wash clothing in hot water and dry on high heat for 55 minutes

Helpful Hint: Create tick kits, one for home and one for on-the-go. Be sure to include:
- Fine point tweezers
- Alcohol swabs
- A plastic baggie
- Magnifying glass or strong reading glasses

Do a full-body tick check daily:
- Check under arms, in and around ears, inside belly button, behind knees, between legs, around waist and especially in hair
- Check your dog for ticks by brushing your fingers through their fur with pressure to feel any small bumps. Check between toes, behind ears, under armpits and around tail and head
  Helpful hint: Adult ticks are only the size of a sesame seed, and nymphs are only poppy seed-sized, so using a magnifying glass or strong reading glasses can help you see them

How to remove an attached tick:
- Use fine-tipped tweezers to grasp the tick as close to the skin’s surface as possible
- Pull upward with steady, even pressure. Don’t twist or jerk the tick; this can cause the mouth parts to break off and remain in the skin.
- Clean the area with rubbing alcohol, iodine scrub, or soap and water
- Save the tick for testing in a jar or zip lock bag according to directions found here: http://www.michigan.gov/documents/emergingdiseases/Tick_testing_flow_chart_227376_7.pdf

Seek medical attention if:
- If you develop a fever, rash, severe fatigue, facial paralysis, or join pain within 30 days of a tick bite
- You develop a bulls-eye rash, even if there is no known tick bite
- Consult your child’s doctor after removing a tick if your child has a chronic illness

For more on Lyme Disease and tick-borne illness and prevention, visit:
- http://www.michigan.gov/emergingdiseases/
  (Spanish information available on this site)
SEEKING FAMILY LEADERS
to serve on our Family Leadership Network

Do you have the desire to grow as a family leader?
Are you able to share personal experiences in a way that informs and empowers others?
If so, and you are interested in providing input on important programs and services for families of children and young adults with special health care needs, then we need you!

The Family Leadership Network (FLN) was created by a collaboration of the Family Center and Family to Family in recognition of the importance of family involvement and our shared commitment to obtaining diverse perspectives and valuable input regarding experiences with healthcare and other systems in Michigan.

Qualified applicants include individuals with a disability or special need, at least 18 years of age, as well as parents, guardians, or caregivers of person with a disability or special need who is 26 years of age or younger. We are seeking two members from each Michigan Prosperity Region: https://www.michigan.gov/documents/msp/Posts_450432_7.pdf

Some of the responsibilities of this position include:

- Participating in quarterly meetings, including a yearly in-person meeting/training
- Identifying local community partners and resources available to special needs families
- Gathering feedback from families in your region and representing their voices on programs, priorities, and initiatives
- Encourage families in your region to use resources and activities sponsored by the Family Center and Family to Family

For more on the FLN, including a full position description: https://f2fmichigan.org/wp-content/uploads/2014/03/FLN-Information-Packet-1.pdf

Hurry! July 28, 2017 is the application due date, get one by copying this link into your browser: https://f2fmichigan.org/wp-content/uploads/2014/03/Family-Leadership-Network-Application-Form.pdf

For questions, or to receive an application by mail, call the Family Phone Line: 1-800-359-3722

Sibshops celebrate the many contributions made by siblings of kids with special needs.

Sibshops acknowledge that being the sibling of a person with special needs is for some a good thing, for others a not-so-good thing, and for many, somewhere in between. They reflect a belief that siblings have much to offer one another — if they are given chance. Sibshops are a spirited mix of new games, new friends and discussion activities.

**Introduction to Sibshops (Day 1 only)** — For parents, caregivers, service providers, educators, community partners, and local health department staff. Attendees who would like to know more about sibling issues and Sibshops, but are not interested in running a Sibshop group would attend Day 1, Friday only.

**Facilitator Training (Days 1 & 2)** — For anyone interested in sibling issues who would also like to learn how to run a Sibshop of their own. Attendees interested in becoming a Sibshop facilitator attend both Friday & Saturday.

We are looking for a few adult sibs and many younger sibs to help us with this great event

- **Adult Sibling Panel** (Day 1 Friday only) — We need 4 to 7 adults, who have a sibling with special needs, to participate on an Adult Sibling Panel on Friday

- **Demonstration Sibshop** (Day 2 Saturday only) — We need 20 young siblings (ages 8 to 13) who have a sibling with special needs to join us on Saturday

For more information on this opportunity, contact the Family Phone Line: 1-800-359-3722

For information on the Sibshop model: https://www.siblingsupport.org/workshops-and-training-on-the-sibshop-model/sibshop-facilitator-training-description
This wonderful non-profit was founded on the premise that each child deserves the chance to reach their highest potential and they will succeed if the community nurtures their abilities and creates an atmosphere for success.

The Family Hope Foundation provides resources, activities, support, and funding for therapies to families of children with special needs in West Michigan. Those needs may be physical, emotional, or developmental.

The Children with Special Needs Fund (CSN Fund)

The CSN Fund enhances the lives of special needs children in Michigan, by providing financial assistance for equipment that promotes optimal health, mobility and development when no other funding source is available.

Families of children aged 21 or younger, who are medically eligible for CSHCS—regardless of enrollment—may apply to the CSN Fund for assistance.

The CSN Fund is supported entirely by donations and is administered through the MDHHS. It may provide partial or full payment for items such as:

- Home wheelchair ramps
- Van lifts and tie downs
- Platform lifts
- Stair* or ceiling* lifts (*both contingent on the availability of specific grants)
- Air Conditioners
- Electrical Service Upgrades for equipment
- Therapeutic specialty bikes/tricycles
- Items not listed, but related to the CSHCS qualifying condition and subject to approval

Find full details on the fund and an application here: http://www.michigan.gov/csnfund/

For an application and/or assistance with an application please contact any of the following:

Ottawa County CSHCS:  616-393-4445
The Family Phone Line:  800-359-3722
The CSN Fund:  517-241-7240

The Family Hope Foundation sponsors many fun family events like:
Sensory Movies at Celebration Theaters (with discounts too), & The Special Families Fun Fest at the DeltaPlex on October 21, 2017

Here’s the Family Hope Foundation’s events calendar: http://www.familyhopefoundation.org/programs/events/upcoming-events

The Brainy Day 5K 10K Run/Walk
August 19, 2017

Now in its’ 11th year, this event was founded by Ottawa County resident, Veronica Constantine, who was inspired to impact others dealing with hydrocephalus or other brain injury after her own diagnosis and recovery.

To date, the Brainy Day Run/Walk has donated $100,000 to various organizations, including $14,000 to Helen De Vos Children’s Hospital.

All proceeds from this year’s race will benefit the newly formed non-profit Brainy Day Fund, created to help West Michigan families directly affected by neurological diagnosis and to educate the community on the long-term effects of brain injury. Their goal is to establish a fund with the Grand Haven Area Community Foundation, so that the Brainy Day Fund will exist for many years to come.

This race qualifies runners for The Mackinac Bridge Labor Day Run. Brainy Day also welcomes anyone who just wants to have fun along the route and help raise money to help others. A kids run will be held on race day; registration for that will be the morning of the race.

Race Date: August 19, 2017
Start Time: 8:00am
Location: 16489 124th Avenue Nunica, MI
Registration Fees — 5K trail run: $27 10K trail run: $37
For details or to register: https://racemine.com/brainy-day-5k/events/2017/brainy-day-5k-10k-trail-run

Brainy Day on FB: https://www.facebook.com/BrainyDay5K

The Family Hope Foundation awards therapy scholarships twice yearly, up to $1,000 per child. The next round of scholarship applications will be accepted from Aug 1, 2017 to Sept 1, 2017.

Find details and an application here: http://www.familyhopefoundation.org/programs/scholarships/guidelines-application

More info at Family Hope Foundation: http://www.familyhopefoundation.org/

Contact them here: http://www.familyhopefoundation.org/contact/contact-us
Special Families’ Corner Facebook Group welcomes all parents and caregivers who are raising children and youth with special needs, regardless of CSHCS enrollment.

Special Families’ Corner Facebook Group was created to help ease the isolation often faced by families raising children and youth with special needs, and to allow parents and caregivers the opportunity to engage in meaningful dialogue with others who can relate!

Sharing experiences, resources, and events
Asking questions of the group, and
Posting items of interest to the special needs community are all enthusiastically encouraged!

Join us here:
https://www.facebook.com/groups/480920718777204/

or search Facebook for:
Special Families’ Corner

For questions contact Amy Fontaine, group administrator and fellow special needs parent: afontaine@miottawa.org

Special Families’ Corner is made possible by the generosity of 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.
Kids’ Corner Activity

Kids’ Corner “Summer Fun” Idea Links:

https://www.realsimple.com/work-life/entertainment/summer-activities
http://www.friendshipcircle.org/blog/2012/06/20/82-summer-activities-for-families-with-special-needs/
https://www.pinterest.com/lisageng/fun-activities-for-kids-including-special-needs/?lp=true