

SPECIAL KIDS' CORNER

News & Updates From Ottawa County CSHCS

February 2024

From the Desk of Leslie Ver Duin, BSN RN

CSHCS Coordinator & Child-Health Team Supervisor

Dear CSHCS Families,

February is best known as a time to celebrate our love for those we hold dear. It's also a time of awareness and advocacy for matters near and dear to the hearts of our CSHCS families—<u>Congenital Heart Defect Awareness</u> <u>Week</u>, <u>International Childhood Cancer Day</u>, and <u>Rare Disease Day</u> to name a few.

On February 16th, we also celebrate all of you on <u>National Caregivers Day</u>! We are inspired by your endless love and dedication, we rejoice in your triumphs, and we weep for your sorrows. We are proud to serve you and feel blessed to support you and your family!

We've gathered some fabulous resources for you in this newsletter, including CSHCS program updates and an introduction to our new nurse, Lauren Potter. You'll find grants and camp scholarships, events, and the first webinars of our spring CSHCS Empowered Parents webinar series. Enjoy!

We are here when you need us! Contact a CSHCS team member (see page three for our contact information), or call the Ottawa County Department of Public Health: 616-396-5266.

Visit our recently updated <u>Ottawa County CSHCS website</u> with important information and answers to Frequently Asked Questions. You'll also find complete information about all Ottawa County children's community health services <u>here</u>.

In health and hope, Kestii Vin Oui

Secured Email Notification:

An email stating "Irene Atwood has sent you a Secured Message" will arrive in your inbox when it's time for your CSHCS Information Review.



Irene Atwood CSHCS Clerk

Around the time of your annual CSHCS program renewal, Irene Atwood, our long-time clerk, will email you via secured message in order to verify your confidential information (address, insurance information, etc.)

Learn how to open your secure message and complete your verification on page one of our <u>Feb. 2023 Special Kid's Corner newsletter</u>.

Avoid Identity Theft: CSHCS will <u>never</u> ask you for your bank account information, account or routing numbers.

If you're ever asked for banking information by someone saying they represent CSHCS, do <u>not</u> share your information and immediately notify CSHCS or your local health department.

Meet Our New CSHCS Nurse Lauren Potter, BSN, RN

Dear CSHCS Families,

Hello, my name is Lauren Potter and I am a new nurse with the Ottawa County Children's Special Health Care Services team. I am excited about my new role! I have enjoyed the opportunity to work with multiple families during my first few months, and look forward to meeting so many more of you.

I have an almost-9-year-old daughter, Avery. In 2018, we followed my parents to West Michigan to be closer to our extended family. We love it on the West Side! Some of our favorite activities include bike rides, tubing on local lakes, going to amusement parks, watching movies, and playing board games. We live on a small body of water and enjoy kayaking, fishing, and paddle boating during the summertime.

I've been a nurse for almost 6 years. I completed my RN to BSN at Michigan State University (Go Green!) after earning my Associate Degree in Nursing at Lansing Community College. My first years of nursing were spent on the Medical Surgical Floor at Zeeland Community Hospital while finishing my RN to BSN program. During that time, I was placed with the Kent County's Health Department for a clinical rotation where I discovered my love for Public Health Nursing.

Shortly thereafter, an opening became available on the Ottawa County Immunization team. I spent three and a half years there until transferring to Children's Special Health Care Services in October 2023. It has been such a pleasure working with the CSHCS team and families so far. I am so thankful to be a part of Public Health in Ottawa County.



Our new CSHCS team member, nurse Lauren Potter, with her daughter Avery.

Ottawa County CSHCS Contact Information

February 2024

Brenda Kempf, Representative

616-393-4445 bkempf@miottawa.org

Contact Brenda for:

- Enrollment & renewal Adding diagnoses
- Billing & insurance • issues
- requests
- Travel & lodging
- Adding providers

- Changes in income
- · Financial concerns
- Changes in insurance, name, address, phone, or email address

Contact Your CSHCS Nurse for:

- Plans of Care & Case management
- Medical questions
- Questions about CSHCS coverage
- Adding a new diagnosis or specialist

Samantha Leffman, BSN, RN 616-393-4442

sleffman@miottawa.org

Lauren Potter, BSN, RN 616-393-4416 lpotter@miottawa.org

Aimee Dekker, BSN, RN

616-393-4440 adekker@miottawa.org

Irene Atwood, Program Clerk 616-393-4439

iatwood@miottawa.org

Amy Fontaine, Parent Consultant

616-402-2275 afontaine@miottawa.org

Leslie Ver Duin, BSN, RN **CSHCS** Coordinator 616-393-4444 lverduin@miottawa.org

Sandra Lake, MPH, BSN, RN OCDPH Community Health Manager • Complaints or complements regarding 616-393-5753 slake@miottawa.org

Nurse for CSHCS families in:

- Allendale
 Grandville
 Hudsonville
 West Olive
 Wyoming
 Holland zip code 49423
 Grand Rapids zip codes in Ottawa County

Nurse for CSHCS families in:

- Grand Haven
- Spring Lake
 Fruitport
 Nunica
 Marne
 Conklin
- Casnovia
 Ravenna
 Coopersville
 Walker
 Holland zip code 49424

Nurse for CSHCS families in:

- Holland zip code
 49422 Jenison
- Zeeland Macatawa
- Byron Center

Contact Irene for:

- · Annual CSHCS Information Update via secure email
- Changes in name, insurance, phone, home or email address

Contact Amy for:

- Special Families' Corner Facebook Group
- Newsletters .
- CSHCS Webinars & Outreach

Contact Leslie for:

- · Questions or concerns related to staff or program operations
- If unable to reach Ottawa County CSHCS staff

Contact Sandra for:

- any staff member
- · Further questions about Ottawa County community programs

CSHCS Program Fax: 616-393-4435

CSHCS Websites:

Ottawa County — Newly updated! State of Michigan **Online Payments** The Family Center for Children and Youth with Special Health Care Needs

Children's Special XXXXXXXX Health Care Services

Otto a Departm Public Health

CSHCS Age 26 Program Expansion Update

The Children's Special Health Care Services (CSHCS) program in Lansing is working to inform and enroll approximately 9,000 individuals who may now be eligible for CSHCS due to the expansion of the program for those up to the age of 26. With state budget approval, the expansion became effective on October 1, 2023. Thank you for your continued patience during this historic undertaking!

Other CSHCS program eligibility requirements still apply, such the need to visit a medical subspecialist at least yearly for one of the 2,700+ CSHCS qualifying <u>medical</u> conditions, meeting condition severity and chronicity guidelines, and being a citizen and Michigan resident. Program benefits and financial obligations also remain the same.

Streamline enrollment by asking your medical specialist's office to submit a medical report (based upon a visit within the last year) to CSHCS in Lansing for eligibility review.

- You'll need to provide them with a signed CSHCS medical release of information form which can be obtained from any of our CSHCS nurses or representative, Brenda Kempf. See page 3 for contact information.
- Once found eligible for CSHCS, you'll receive an invitation to join. Fill out and return your enrollment application, including the financial form, to CSHSC in Lansing.

For questions or help with CSHCS enrollment or re-enrollment, or to learn what is needed to determine your eligibility, please contact any of our nurses or representative, Brenda Kempf. See contact information page 3. Here's a link to helpful answers to <u>FAQs about the Age 26 expansion</u>.

On February 21st at 11:00 am a <u>CSHCS Age 26 Expansion webinar</u> is being hosted by the Family Center for Children and Youth with Special Health Care Needs, the parent-directed section of CSHCS. See the flyer below for details and a registration link.

*There are a few conditions that are eligible for CSHCS regardless of age, such as Cystic Fibrosis, Sickle Cell Disease, and some bleeding disorders.



News & Updates (continued)

2024 Arc of Michigan Tax Guide



For 50 years, the Arc of Michigan Tax Guide has been an invaluable source for information about tax deductions and credits related to the care and support of a child or adult with an intellectual or developmental disability. **Find it here:** <u>Arc of Michigan's Income Tax Guide</u>

Michigan Disability Parking Placards



According to the Michigan Secretary of State, you may be eligible for a disability parking placard if your child has a qualifying disability, such as:

- blindness
- · any condition that significantly limits their ability to walk
- any condition that requires a wheelchair, walker, crutch, or other assistive device*.

To apply for a disability parking placard, fill out this <u>application form</u>, have it completed and signed by your child's doctor/licensed medical professional, then fax it to: 517-636-5865. You can also mail it to the address on the form or bring it to your local Secretary of State branch.

You can now renew a permanent disability placard <u>online</u>. If you'll be renewing a temporary disability placard, you'll still have to mail it or bring it to your local Secretary of State branch.

* This can include a person physically helping the child with mobility or safety.

TSA Cares: Security Screening Assistance

Did you know that you can contact <u>TSA Cares</u> to request assistance during security screening from a Passenger Support Specialist?

A Passenger Support Specialist (PSS) receives specialized training, including how to effectively assist and communicate with individuals who have disabilities or medical conditions. A PSS can be especially helpful for passengers who need additional assistance during security screening due to the following:

- Difficulty following instructions due to a disability or medical condition.
- Having internal/external devices that may affect your ability to use screening technology.
- Traveling with medically necessary liquids, gels, or aerosols over 3.4oz.
- Traveling with a child who has a disability or medical condition.
- Traveling with a service animal.

To request assistance, contact TSA Cares at least 72-hours prior to your departure by completing the <u>TSA Cares form</u> or calling TSA Cares: 855-787-2227.

Traveling with a Hidden Disability: The Sunflower Program



The Gerald R. Ford International Airport is now participating in the <u>Hidden</u> <u>Disabilities Sunflower Program</u>, a global initiative to provide support and assistance to travelers with hidden disabilities.

The Hidden Disabilities Sunflower (worn in a lanyard, pin, wristband or retractable ID card) enables individuals to discreetly indicate to trained airport staff and partners that they have a non-visible disability and may need accommodations, additional assistance, understanding, or more time.

Passengers with hidden disabilities can request a free Sunflower item at the Airport's Visitor Information Desk and security screening checkpoint.



Ottawa County CSHCS Empowered Parents Webinar



Help for navigating life with special needs

Open to parents, caregivers, and professionals **FREE!** Registration is required (see below)



Summer Camp Opportunities for Children & Adults with Special Needs

Wed., February 28, 2024 — Noon to 1:00pm

Grab your lunch and join us on Zoom to:

- Discover the benefits of attending summer camps for those with special needs.
- Learn about Family Center camp scholarships and other funding resources.
- Hear from the directors of three amazing spotlighted camps: Camp Sunshine, Camp Fish Tales, and Indian Trails Camp.

Attendees will also receive a 2024 Michigan Summer Camp Guide for Families with Special Needs Children and Adults Guide.



To Register: Send your name and email address to Email: <u>afontaine@miottawa.org</u> or Call/Text: 616-402-2275

Note: If you're unable to attend our CSHCS webinars virtually due to technology or child care issues, please contact our parent consultant to discuss support options such as childcare reimbursement or an alternative viewing location. Her contact information is the same as for registration.

Ottawa County Empowered Parents Webinars are made possible, in-part, through a generous grant from the Family Center for Children and Youth with Special Health Care Needs, the parent-directed section of CSHCS. Contact the Family Center by calling the Family Phone Line: 800-359-3722 or by emailing: cshcsfc@michigan.gov.

Upcoming Empowered Parents Webinars!

If there's a webinar topic, or presenter you'd like us to host, please send your suggestions to: <u>afontaine@miottawa.org</u>.

March 20th at Noon: "Michigan Medicaid Waivers: What they are and how to access them" with Jan Lampman.

April (Date TBD): Self-Directed CMH Services, presentation and parent-panel discussion.

May (Date TBD): Organizations for Pre-employment Skills Training and Shining a Spotlight on Local Businesses Supporting Persons with Disability and I/DD.

June & July: Dates and topics to be determined.

August: Fellinlove Farm Family Fun Day (in-person event) with area community agencies. Date to be determined.

NOTE: Webinar flyers will be shared when final details are confirmed. Registration will be the same as that listed for our camp webinar above.

Special Families' Corner Facebook Group

The Special Families' Corner Facebook group was created by Ottawa County CSHCS for parents & caregivers of children or young adults with disabilities or special needs. We also welcome adults with chronic health conditions or disabilities themselves.

- Discover events, grants & community resources
- Learn about news & issues affecting families
- Find support from fellow parents & caregivers
- Become a part of our growing community!

Just search Facebook for <u>Special Families' Corner</u> & request to join. Be sure to answer the membership questions too. Only group members can view posts in this closed group. CSHCS enrollment is <u>not</u> required to join.

Special Families' Corner is made possible by a grant from The Family Center

The Family Center for Children & Youth with Special Health Care Needs (the parent-directed section of CSHCS) The Family Center can help with: Call the **Family Phone Line:** CSHCS Enrollment & Program Assistance 1-800-359-3722 • Conference & Camp Scholarships (See page 8) or email: Resources for Your Family & Child's Diagnosis cshcsfc@michigan.gov Transition Support for Youth & Families Parent-to-Parent Support Network. Trained parent Family Children's Special mentors, who have a child with a similar diagnosis, Health Care Service can offer support, guidance, and help with finding resources Note: The Family Center serves all children and youth who have, or are at an increased risk for, physical, developmental, behavioral, or emotional conditions, regardless of CSHCS enrollment



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March Parent Connect Call (A Microsoft Teams Webinar) Wednesday, March 13, 2024 4:00 pm — 5:00 pm



"Can't We All Just Get Along? Overcoming Barriers and Building Relationships in Healthcare"

Parent facilitators, Lisa Huckleberry from the Family Center, and Kristen Reese from Michigan Family to Family will identify common barriers, share ideas to overcome them, and create strategies to build stronger relationships with your child's provider.

This interactive webinar is a great opportunity to connect with other parents, participate in shared learning, and create an action plan to improve your family's healthcare experiences.

Click here to register on Eventbrite

Contact The Family Center with questions: 1-800-359-3722

Family Center Camp Scholarships



Parents/Caregivers of a child/youth with special health care needs are invited to apply for a camp scholarship (up to \$350) from the Family Center for Children and Youth with Special Health Care Needs (Family Center). Camp Scholarships are made possible by funding from the <u>Children with Special Needs (CSN) Fund</u>.

Camp scholarship applications are accepted from February 1, 2024 until all funds are awarded. Funding is limited, and only 10 scholarships are awarded per camp so apply as soon as possible!

Who may be eligible?

- Michigan residents up to the age of 21 who have a special health care need (medical, developmental and/or behavioral condition). Camp Scholarships are <u>not</u> limited to CSHCS enrollees.
- Anyone who is <u>not</u> enrolled in CSHCS is required to submit a letter from their specialty provider verifying their diagnosis/special health care need.
- Applications for multiple family members are now being accepted, though each individual camper can only receive a scholarship every other year.

Camp guidelines: Camps must be licensed in Michigan, though exceptions are made for camps operated by a university, school district, or city/ township parks and recreation programs. Virtual camps are also considered, as are out-of-state camps on an individual basis.

Find an application here: 2024 Family Center Camp Scholarship form.

For questions, or to request a paper application, call The Family Center Family Phone Line: 1-800-359-3722 or email: <u>cshcsfc@michigan.gov</u>.

MI CEC CAMPERSHIPS for students with an IEP



Camperships of up to \$250 are available from the Michigan Council of Exceptional Children (MI CEC) to eligible Michigan students with an active IEP.

Who is be eligible? Students who are Michigan residents with an active Michigan IEP who are in need of financial support and would otherwise not have an opportunity for a summer camp experience.

Camp guidelines: This is an opportunity to apply for funding (up to \$250) to attend a summer camp in Michigan (some exceptions may be made for specialized camps outside of Michigan). Transportation and financial arrangements are the responsibility of the family.

Electronic applications, including a letter from the student's teacher or principal attesting to the student's 2023-24 IEP, must be submitted by April 15th, 2024.

Apply here: MI CEC Campership Application

For questions please email: <u>camperships@michigancec.org</u>



MICHIGAN

CSN Fund Grants

The Children with Special Needs (CSN) Fund provides financial assistance to families for the purchase of equipment or services for their child when no other funding source is available.



enhancing the lives of children with special needs since 1944

To apply for a CSN Fund grant, a child must by under age 21 and enrolled in, or eligible to enroll in, Children's Special Health Care Services (CSHCS). If your child is not enrolled in CSHCS, you must submit medical information detailing his/her CSHCS-eligible diagnosis, along with a **letter of medical necessity** from the child's medical subspecialist for the equipment that is being recommended.

Many types of equipment may be covered by a CSN Fund grant. You'll find examples on both the <u>CSN Fund website</u> and on the <u>application form</u> itself. Information is also available for limited <u>ceiling and stair lift grants</u> that are sometimes available depending upon funding availability.

For help with a CSN Fund grant application, contact any CSHCS team member. See page 3 for our contact information. You may also request assistance or ask questions at the Family Phone Line: 1-800-359-3722.



Lori's Voice provides financial assistance to families who are unable to afford adaptive equipment, travel, therapy, and items not fully covered by insurance or other organizations.

To be eligible for financial assistance for <u>Lori's Voice</u>, a child must be under the age of 21 with mobility issues due to a neuro-muscular or degenerative disease with a financial need.

Click here to learn more about Lori's Voice and to find an application.

Family Hope Foundation Therapy Scholarships

The Family Hope Foundation (FHF) scholarship program provides financial assistance to families that have little or no insurance coverage for the therapies that help their children.

FHF has two scholarship cycles, one in the spring and one in the fall. Families can apply for scholarships up to \$1,000 during one or both scholarship cycles.



The application deadline for FHF Spring 2024 Therapy Scholarships is <u>Friday, March 1st by 5 pm</u>.

- Applicants must live in West Michigan (Oceana, Newago, Muskegon, Ottawa, Kent, Montcalm, Ionia, Allegan, Barry, Van Buren, or Kalamazoo Counties).
- <u>Scholarship Guidelines</u> MUST be read thoroughly prior to completing the application. Applications that do not follow the Scholarship Guidelines will not be considered for funding.
- Late applications will <u>not</u> be accepted.
- Click here to <u>learn more and find an application</u>.

To stay in the know about scholarship and grants that are available to support special needs families, events, and so much more, be sure to join our parent/caregiver support group <u>Special Families' Corner Facebook group</u>!



Rare Disease Network's Rare Disease Gathering

Friday, February 24, 2024 9:00 am — 4:00 pm

Prince Conference Center Calvin University | Grand Rapids, MI

Event titles are live links to event details and registration

The theme for the 5th annual gathering is **Family Odyssey: From Diagnosis to Research to Treatment**. Featured keynote speakers will discuss the advances in genetic testing and treatment that have changed the rare disease landscape. Breakout sessions will provide opportunities to learn more about genetic testing, discover ways to support siblings of children with a rare diagnosis, learn strategies for coping with stress, connect with adults living with a rare diagnosis, and explore rare disease-focused careers.



Michigan Council of Exceptional Children Conference

February 28, 29, & March 1, 2024 Amway Grand Plaza Hotel | Grand Rapids, MI

The 84th annual MI CEC conference brings special education stakeholders, parents, teachers, and administrators together for sharing and learning. This year's theme is "An Exceptional Celebration" with keynote speaker, Dr. Muhammad Khalifa, and over 80 break-out sessions.



START Project Conference

Monday, April 22, 2024 8:30 am — 3:30 pm The Kellogg Center | East Lansing, MI

The focus topic of the Statewide Autism Resources & Training (START) Project's 23rd Annual Conference is **Creating Connections: Strengthening Belonging** for students who have Autism Spectrum Disorder. See the full conference agenda and speaker information <u>here</u>.

The START Project offers a limited number of **Family Scholarships** to Michigan family members of a child with a disability to cover the cost of registration for the START conference. <u>Apply here</u>.



Navigating Health Care Training for Parents of Children with Epilepsy

Saturday, March 16, 2024 9:00 am — 3:30 pm (with a lunch break) Virtual Meeting on Zoom

<u>The Michigan Pediatric Epilepsy Project</u> is partnering with <u>MI Family to</u> <u>Family</u> and the <u>Family Center for Children and Youth with Special</u> <u>Health Care Needs</u> to offer this virtual learning opportunity for parents of children with epilepsy (seizures) in Michigan.

This medical advocacy training is offered to provide parents with information, tools, and resources to better navigate the healthcare system for their child.

Topics covered: navigating a new diagnosis; where to find reliable information and resources; how to prepare for a successful health care interaction; improving communication and building partnerships with health care providers; becoming a good advocate; helping your child be active in their own care; self-care for caregivers; and peer support.



Ottawa County Sibshops — Winter/Spring 2024

Saturdays 9:00 am — 11:00 am March 2, April 13, May 4 Engage Therapy Center | 10263 Chicago Drive | Zeeland, MI

Brothers and sisters, ages 6 to 13, who have siblings with special needs, disabilities, and chronic illness have a group that's just for them! Sibshop are peer support groups that offer a safe and engaging space for siblings to learn, have fun, and meet and be supported by other children who understand what it's like to have a sibling with special needs. There is a \$10 fee/session, scholarships may be available.

Register with Andréa Vugteveen, Sibshop facilitator.

email: amvugteveen@gmail.com or call 616-460-3781.

Find Ottawa County Sibshops on Facebook.



EVENTS (cont.)

Michigan Leadership Education in Neurodevelopmental and Related Disabilities (MI-LEND)

The application period for the 2024-2025 Michigan Leadership Education in Neurodevelopmental and related Disabilities (MI-LEND) is now open.

MI-LEND is an interdisciplinary leadership training program that prepares Michigan's emerging leaders in disability with the goal of improving the health of infants, children, and adolescents with or at risk for neurodevelopmental disabilities and other related health care needs.

Trainees may be individuals with a disability (self-advocates) or a family member (parent or sibling) to someone with a disability, among others. Applicants can be from anywhere in Michigan.

See the full list of who may apply, along with MI-LEND program and application requirements <u>here</u>. Answers to FAQs can be found <u>here</u>.

MI-LEND trainee applications are due on Wednesday, May 1, 2024.

MI-LEND is a collaborative effort of the Family Center for Children and Youth with Special Health Care Needs and these seven universities:

Central Michigan University, Michigan State University, Northern Michigan University, University of Michigan (Ann Arbor), University of Michigan-Dearborn, Western Michigan University, and Wayne State University (program lead).



Webinars from Michigan Alliance for Families (MAF)

View MAF's upcoming webinar schedule here.

Michigan Alliance for Families (MAF) hosts frequent webinars to educate families on a variety of Michigan special education services topics.

Michigan Alliance for Families provides information, support, and education for families who have children and young adults (birth to age 26) who receive, or may be eligible to receive, special education services.

The <u>Michigan Alliance for Families website</u> can help you find information on special education issues, as well as disability-specific information.



Leaders in Policy Advocacy (LIPA) from Michigan Alliance for Families

Leaders in Policy Advocacy (LIPA) is a leadership development program for adults with developmental disabilities and parents of minor children with developmental disabilities. LIPA trains and supports participants to become leaders in the disability rights movement.

Topics include: Disability History; Inclusive Education; Assistive Technology & Social Media; Self-Determination, Alternatives to Guardianship; Person-Centered Planning; Access to Housing & Employment; Public Benefits & Systems of Support; and Systems Change.

LIPA is a hybrid program of both in-person and online trainings. Lodging, meals, and stipends to cover necessary travel expenses and child care will be provided to encourage participation.

2024 Training Dates:

Weekend 1:	April 19-20 in Lansing
Weekend 2:	May 17-18 in Lansing
Weekend 3:	June 21-22 Online
Weekend 4:	July 19-20 Online
Weekend 5:	August 16-17 in Lansing
Weekend 6:	September 20-21 in Lansing

Learn more about LIPA here.

Apply by February 29th here.

Disclaimer: Special Kids' Corner Newsletters contain information and resources (with internet links) that may be useful to families with special needs. The content is for your consideration only and not endorsed by Children's Special Health Care Services of Ottawa County.