



OMS OMS Passport Education Support

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OMS MEDICAL PASSPORT

- ▶ The purpose of a medical passport is to allow adolescents/young adults/adults independently explain to medical providers what OMS is and how it affects them.
- ▶ It also explains what treatments have been the most effective for them.
- ▶ This has been requested by many OMS adolescents and adults as treating doctors have not understood or believed their diagnosis. Treatment has therefore been denied or not appropriate.



OMS Medical Passport Continued

- Many neurologists are not familiar with this rare diagnosis. We need to support the increasing number of OMS patients as they become increasingly independent.
- We hope that this “passport” will help adolescents, young adults, and adults better explain what OMS is and what treatments help to allow their doctors to provide the best medical support especially when they are having a relapse.
- We continue to learn how OMS impacts some individuals as they mature and know that we will continue to learn more to provide better support.



Passport Contents

- **My Medical Passport**

- My Information:

- Attach Photo here ?????

- Name:

- I like to be called:

- Date of Birth:

- Age:

- Address:

- Social Security Number: ????????????????????

Page 1



My Job/Program Is:

People to contact for additional information:

Spouse:

Address:

Phone Number:

Parents:

Address:

Phone number:

(multiple names and numbers an option)

Friends:

Name and Number:

(multiple names and numbers an option)



Additional Providers:

Case worker: (*name and number*)

Power of Attorney ????

Guardianship:

Guardian: (*name and number*)

My PCP:

Name:

Address:

Number:



OMS: Definition

Opsoclonus-myoclonus-ataxia syndrome (OMS), also referred to as “Dancing Eyes Syndrome” (DES) is a rare autoimmune disease that affects the brain. Autoimmune diseases cause the body’s immune system to react against itself and attack its own healthy tissue. In OMS/DES, the immune system reacts against certain components of the brain. The main target of the attack is believed to be the cerebellum. This attack is what causes the symptoms of OMS/DES. Initially these symptoms can be severe, and include spontaneous, abnormal, chaotic eye movements (opsoclonus), spontaneous random limb jerking (myoclonus), and incoordination (ataxia). Even if these physical symptoms resolve, up to 70% of patients may experience residual cognitive and behavioral symptoms, including speech and language problems and aggression. Other residual symptoms can include reading difficulties, dysregulation and anxiety.



How did/does OMS affect me:

I had a neuroblastoma:

It was treated with:

In school, I have/had these problems:

????????????????

Language deficits

Receptive (understanding what is said to me)

Expressive (ability to expressive my thoughts)

Reading delays

Writing delays

Mathematic delays

Attention difficulties

Developmental delays

Autism

Currently:



My neurologist is:

Address:

Number/email/pager:

Relapses:

I have not had a relapse:

I tend to relapse when:

My last relapse was on:

When I relapse, I respond to the following treatment(s):



My Medication:

Current Medication:

Name:

How Often:

Dose:

Route/Form

Replicate ?????

Allergy Medication: ????????????????????

Name:

How Often:

Dose:

Route/Form:

Replicate



Recent Medical History:

Last time hospitalized:

Issues:

Long term conditions:

Vaccinations:

My vaccinations are up to date:

I cannot be vaccinated as it
causes a relapse:



My Spirituality:

????????????????????

Faith:

What this means to me:



OMS Survey

- ▶ We are working on a survey to be sent to young adults with OMS to better understand what individuals with OMS would like the “passport” to reflect and request. We appreciate everyone’s support with this endeavor. If you are interested in receiving this questionnaire, please email mike@omslife.org so that we can include you on our survey.



Education Support



Preschool Quandaries





Preschool- To Attend or Not to Attend The Dilemma.....

- ▶ Many children with OMS do attend preschool; some attend an integrated preschool through their public school if their difficulties need continuing support services
- ▶ They may stay home when the flu, colds, etc. are going around
- ▶ They will miss school because of medical appointments
- ▶ If they have continuing impacts of their diagnosis of OMS, they might be able to receive therapies (speech and language, OT, and PT) as well as cognitive, social, and behavioral support.

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Preschool Continued

- Some children continue to be immuno-compromised and/or their parents are reluctant to have them exposed to the viruses and illness present in a preschool.
- For some children with OMS a relapse is known to be correlated with a virus.
- Try to work with the Public School's Early Childhood Coordinator.
- Since your child may be too medically vulnerable to attend school, support may be arranged through the preschool to provide supports at home for a child with OMS.



Preschool Options: If you are keeping your child at home

- Request online contact with the preschool class through Skype and /or Facetime are valid options.
- Circle time would probably be a good place to start with music time another good time to join in.
- If the school is willing, some speech and language therapy, social skills, OT, and PT support might also be provided in the home (These therapies remain difficult to provide online but online homeschool districts often have experience in this.) The preschool teacher might be able to send home two or three activities that students in the class will be completing.

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Preschool Suggestions

- ▶ Try to work with the teacher to make your child feel a part of the class.
- ▶ As your child's health improves, these connections may reinforce friendships in the future when your child is able to attend school (even if part time.)

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Education Support

- Questions that parents of children with OMS frequently have when they struggle with reading.



Language and Reading Delays

- ▶ Research has shown that OMS patients are vulnerable to language and reading delays
- ▶ Teachers and educational professionals are not aware of or perhaps believe in these vulnerabilities for an OMS child
- ▶ Parents need to remain vigilant to make sure that their child with OMS is receiving the support that they need.



Warning... Be on Alert.... Signs

- Generally, children who are receiving speech and language therapy are closely monitored for early reading delays.
- In Kindergarten, if your child is struggling to remember the name of a letter or it's corresponding sound ask for early intervention including Title 1 support or Response to Intervention (RTI) as a first round of intervention.
- If he/she is still struggling in March, please request that your child receive a full evaluation (IQ testing, academic testing, speech and language therapy) through the public school system (US regulations) to see if they are eligible for support through an Individualized Education Plan (IEP) or just continue with some reading support.



Dyslexia

- ▶ Some children have good memory skills and can memorize sight words and spelling words, but can't use phonic skills to help them decode unfamiliar words.
- ▶ Dyslexia is genetic... Question- what percentage of children with OMS have parents with a history of dyslexia? Would be interesting to know/find out....



Upper Elementary and Middle School

- ▶ Some children with reading difficulties have strong memory skills. They can learn to read and can be very fluent, but by the end of the elementary and middle school reading becomes more complex, abstract, and requires inferential reasoning- again another language task. They may falter and their lack of understanding in what they are reading can easily be disguised by excuses, avoidance, behavioral issues, not turning in homework, etc.at least, for a while...
- ▶ So reading is a journey... stay there with your child..... Monitor... Remember to ask for support



Future Topics

- ▶ Another issue for OMS children is attention and behavioral issues. This too is ongoing and impacts their ability to do well in school. This is a subject that parents frequently have questions and needs to be explored further.