DIY Medical Records

- **Examples of some available:**

1) from MSF
https://moebiussyndrome.org/working-with-healthcare-professionals/

2) from Family Voices -ECAC
https://www.ecac-parentcenter.org/wp-content/uploads/CareNotebook-English-Completely-Fillable.pdf

- **Why Keep Records?**

for.....

- care team
- teachers
- school health forms
- doctors and therapists
- respite care
- long term care
- future research studies

because....

- Memory is not reliable over the years (and decades!) to come.
- A hard copy may needed for verification in the future for medical or legal reasons.
- New research or learning might be applied to re-interpret old data.

- **What is a DYI - MR?**

Your tool to help you organize medical information and to facilitate communicate with your care team, teachers and medical providers. Your system does not have to be in any strict sequence or format, but rather one that is logical to you and easy for you to maintain. This is an organized collection of important medical events, data and information.

● **How does a DIY-MR differ from a medical history?**

A standard Medical History is a standard set of information used to relay information to other physicians:

1. Chief Complaint
2. History of the Present Illness
3. Past Medical History (including Medications)
4. Social History
5 .Family History
6. Review Of Systems
7. Physical Exam
8. Labs, Radiology
9. Problem List
10. Plan

It is helpful to understand this system, but you do not have to organize your records in this way.

● **What a DIY-MR is not:**

While photos might be included in your DIY-MR, this is **not a scrapbook or a Babybook** (though you might want one of those, too!)

Not an IEP...but can include your IEP, if you wish. IEP documents can be extensive and add up over the years, so a separate notebook, by year, may be a good separate system.

● **Information that might be included** in DIY-MR

1. legal forms (copies of these, not originals) such a guardianship papers; custody papers; advanced directives
2. insurance information
3. birth records
4. growth charts--charts, or NIH graphs (use consistent measurements systems!)
5. developmental milestones-----> NIH tracker
6. caretaker entries
7. medication records
8. allergies and adverse reactions to meds
9. list of medical providers
10. list of medical facilities used
11. list of sources for medical supplies

12. special instructions : anesthesia *; seizures; emergency care
13. resources to educate others:
    - MSF brochures to have handy to distribute to teachers and providers
    - reference articles or papers to provide to medical personnel or teachers
    - your own personal notes

- **How to request copies of medical documents**

https://www.healthit.gov/how-to-get-your-health-record/get-it/

- **How to organize :**

Hard copies such as a 3 ring binder
Digital files
?? Both

- **Supplies for a hard copy**

3 ring binder
tab dividers- ones with pockets or color coding can be handy
clear page sleeves (thinner for one page and thicker ones for documents)
business card page
3- hole paper punch
sticky notes or temporary page tags
printer paper or 3 hole lined notebook paper

- **Organizational options**

File by date (front to back, or back to front)
File by body system or medical problem, and then by dates
    feeding
    breathing
    neuro, or special issues such as eye care
    orthopedic
Lab tests can be separate or included, entered by date
Index in front with a spreadsheet for easy reference**:
    Major events such as hospitalizations and surgery
    Evaluations and testing (EEG, EKG, pulmonary testing, feeding challenges)

- **Maintenance**

Add: Try to add new documents as soon as possible. Ask providers if they can give you a paper summary after each visit, or download a copy of a medical visit from the provider EHR system. Make a place to keep new papers in the front or back of the book until you have the time to file them properly.

Understand: If there is something that does not seem to make sense, ask for help. EHR's may have incorrect information*; check information and correct asap!

Educate: Learn more about new issues, and add that information to your resources page.

** INDEX page concept

date	procedure	provider	facility	notes

References:

1. A framework for the evaluation of facial weakness:
https://pmc.ncbi.nlm.nih.gov/articles/PMC8028830/

2. Multidisciplinary care for Moebius management protocol:
https://pubmed.ncbi.nlm.nih.gov/38893020/

*3. Intubation and anesthesia care with Moebius patients:

https://pubmed.ncbi.nlm.nih.gov/16189336/

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Ferguson S. Moebius syndrome: a review of the anaesthetic implications. Paediatr Anaesth. 1996;6(1):51-6. doi: 10.1111/j.1460-9592.1996.tb00354.x. PMID: 8839089.

4. NIH growth charts:
https://www.cdc.gov/growthcharts/cdc-charts.htm

5. NIH developmental milestones:
https://www.cdc.gov/ncbddd/actearly/milestones/index.html