Keeping Medical Records

DIY Workshop for Parents, Caregivers, and Adults with Moebius syndrome

Moebius Syndrome Foundation Conference

July 27, 2025

Meet our speakers

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Let’s get started.

Why Keep Records?

For...

- Care team
- Teachers
- School health forms
- Doctors and therapists
- Long term care
- Future research studies

Because...

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

What is a DYI-MR?

Example from the Moebius Syndrome Foundation

Example from Family Voice - ECAC

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:

- A scrapbook
- A baby book
- An IEP

- You might want one of these too!
- 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

Medical Binder Method

- Ideal for shorter periods of time
- Easy to grab what is needed most frequently
- Very portable

File Box Method

- Ideal for longer periods of time
- More detailed files
- Add in IEPs
- Can be easily grabbed in case of evacuation

Examples

Information That Might Be Included in a DIY-MR

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

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:
    a. MSF brochures to have handy to distribute to teachers and providers
    b. reference articles or papers to provide to medical personnel or teachers
    c. your own personal notes

Start Building...

01

How to Request Copies of Medical Records

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

02

How to Organize

Hard copies, such as a 3-ring binder

Digital Files

Combination of both

03

Supplies for a Hard Copy

3 Ring Binder, with pockets and a clear front

Tab Dividers - Ones with pockets or color coding may be handy

Clear Page Sleeves (thinner one for one page and thicker for documents)

Business Card Page

3-hole punch paper or punch

Sticky Notes or temporary page tabs

Printer paper or 3-hole lined notebook paper

Organizational Options

01

File By Date

Front to back or back to front

02

File by Body System/Medical Problem

File by body system or medical problem, and then by dates

- Feeding
- Breathing
- Neuro, or special issues such as eye care
- Orthopedic

03

File by Category

Lab tests can be separate or included, entered by date

04

File by Index or Event

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.

Digital Records

Managing Digital Records

- Many major medical systems use MyChart, which allows you to see all of your records, including notes from providers, letters between providers, discharge instructions, visit summaries, etc. in one place
- Many medical systems also have their own portal, which may or may not be linked to a larger hospital system

- Keep a list of passwords for each of your portals. You can use a digital password keeper, like NORD Password Manager or LastPass , or secure them at home in a safe storage place. Change your passwords often!
- You can print off documents from one portal and bring to another doctor. However, this might make some doctors angry, because they want to manage the records officially, and not have you be the go-between. It's best to have the offices transfer the paperwork officially!
- You can minimize digital record confusion by staying within one medical/hospital system. The trade-off may be choice in doctors and/or quality of care and expertise.

Third Party Apps

- Any time you use a third-party app or program, you are giving up your personal data

- Medical apps are not legally regulated the same way as medical records.
    - You are opting in to share your medical data with an app. It goes to the company who runs the app, Apple or Google, and third-party companies like Adobe and other marketing databases.
- App data is sold, usually anonymously and in bulk, to advertisers and companies who want to sell you something.
    - A period tracking app may be used to learn you are expecting and send you a box of formula
    - You may have a BMI that is overweight, and you will be shown ads for weight loss workouts and/or supplements

Managing Data Leaks

Digital Medical Records always are at risk of data-leaks from hackers.

Some examples:

- Your hospital system is targeted with ransomware and cannot access your medical records
- Your doctor's office records are hacked, leaking your social security number, telephone number, and personal home address onto the Dark Web

In situations like this, you should be notified by the organization that was hacked. These often come in the mail, in a plain envelope, with black and white messaging. They should tell you: the name of the office that was compromised, the name of the database, and what personal information was leaked to the hackers (e.g. your name and phone number).

How to Protect Yourself After A Data Leak

- Change your passwords immediately
- Don't use the same password across multiple sites/organizations
- Enable 2 factor authentication (2FA) using an authentication app or the strongest protection the site offers (e.g. email code, phone text)
- Review your account activity. Make sure you don't have any false transactions, especially on your credit cards, bank statements, and medical bills.
- Place fraud alerts with the major credit bureaus (Equifax, Experian, and TransUnion)
    - If you have a child under the age of 18, you can freeze their credit until they are an adult.
    - If you are an adult, you can freeze your credit and unfreeze it only when needed (e.g. getting a credit card, buying a car or house).
    - Freezes and Fraud Alerts must be placed with all three agencies, separately.

Workshop + Q&A

Thank you

Questions? Contact:
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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

6. File Box: https://www.containerstore.com/s/office/paper-storage/weathertight-file-box/12d?productId=10027141

**Index Page Concept:

Date	Procedure	Provider	Facility	Notes