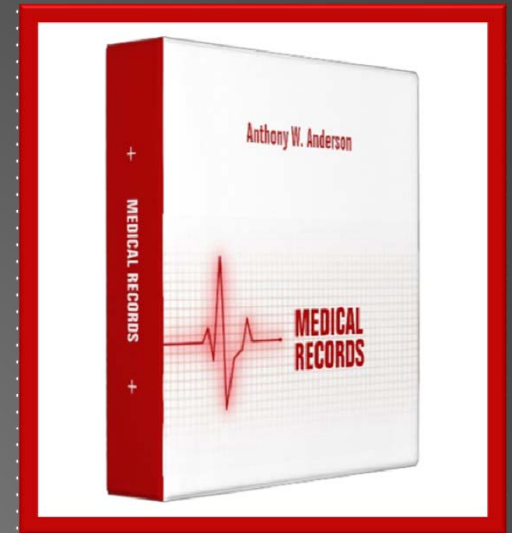


# CARING FOR A CHILD WITH MEDICAL NEEDS



# TOPICS COVERED

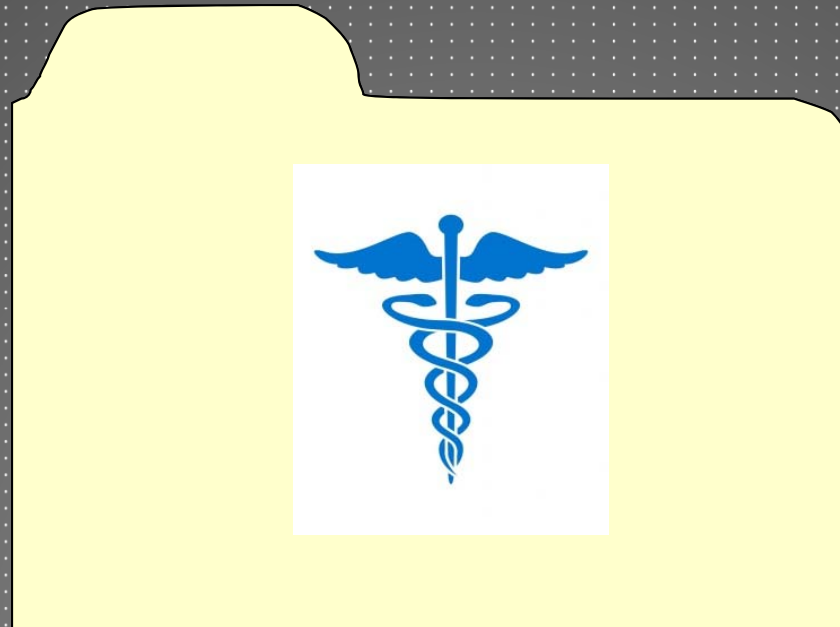
- Organizing Medical Records
- Record Keeping Tips
- Creating a Medical Notebook
- Tips on Handling Medical Appointments
- “My Chart”- Online Health Connection



# ORGANIZING YOUR RECORDS

- Start today, this month, this year
- Don't let the overwhelming thought of organizing prevent you from beginning
- Find a method that works for you and use it
- The best method is one that you will use regularly.

# HOW TO START ORGANIZING YOUR RECORDS?



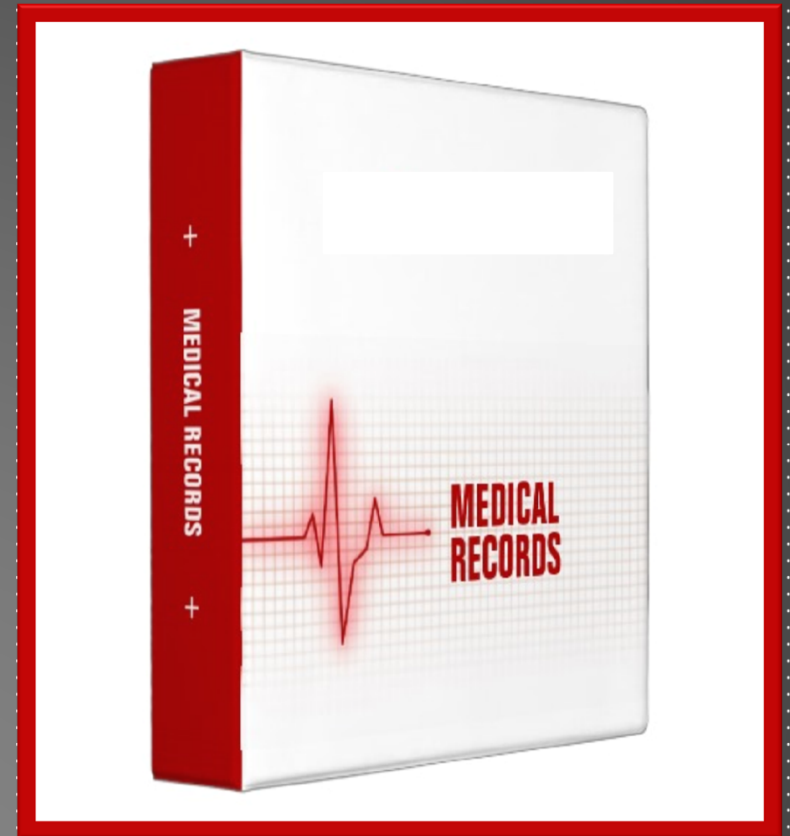


# RECORD KEEPING TIPS



# WHY KEEP RECORDS?

- It is important to have medical information in one easily accessible place.
- Keeping track of your families medical information can prevent unnecessary stress.



# WHY KEEP RECORDS? (CONT.)

- If you move or change doctors you will be able to share your medical history



# WHAT SHOULD YOU KEEP?

- Medications list
- All relevant information related to the child
- Contact information and dates of service



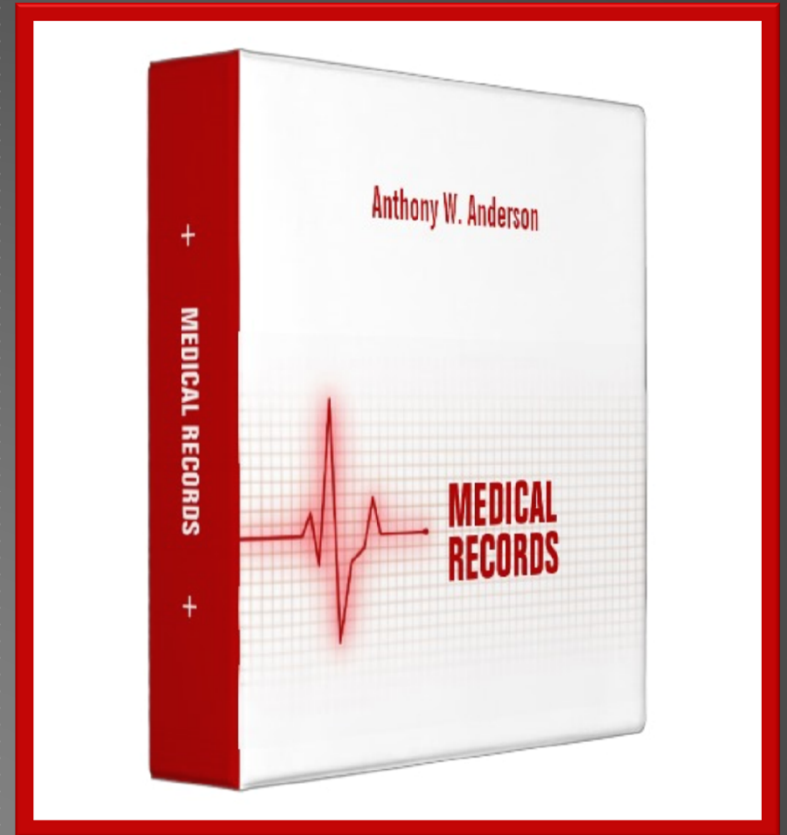


# WHAT SHOULD YOU KEEP? (CONT.)

- Insurance Information
- Education/School Documents
- Equipment Information
- This does NOT need to all be in one place



# MEDICAL NOTEBOOK



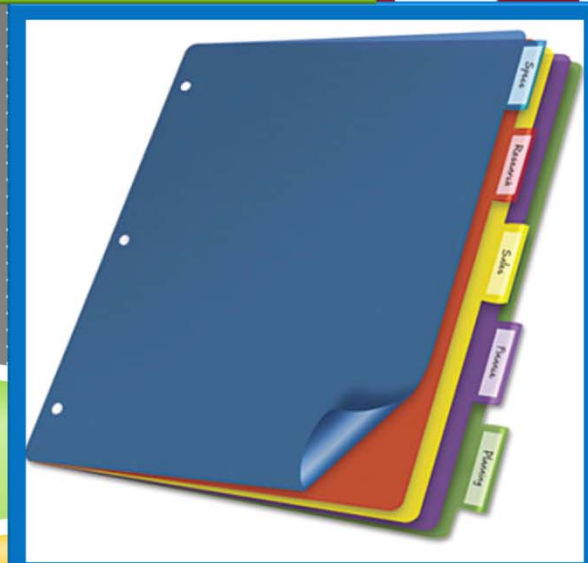
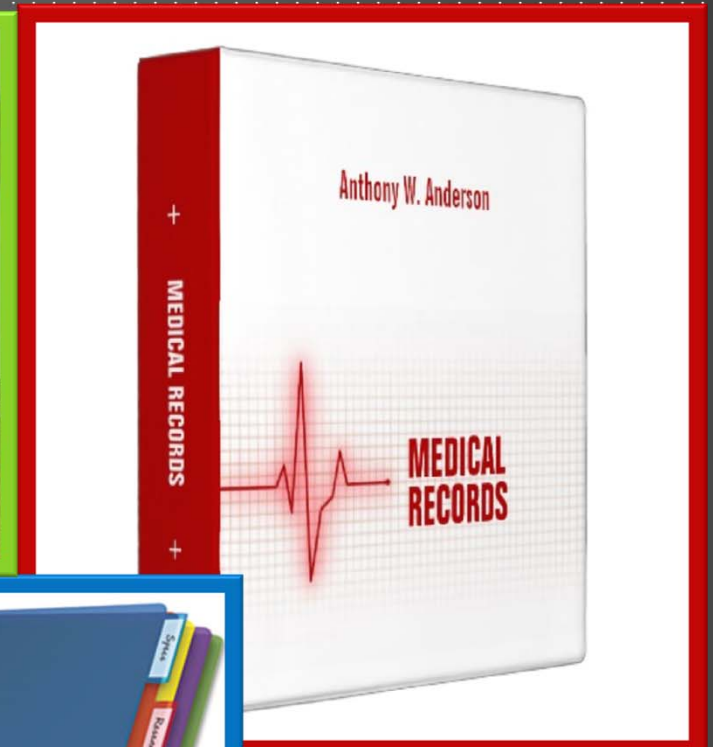
# MEDICAL NOTEBOOK

➤ Binder

➤ Tabs

➤ Paper

➤ Pen



# MEDICAL NOTEBOOK

- Each specialist should have their own page

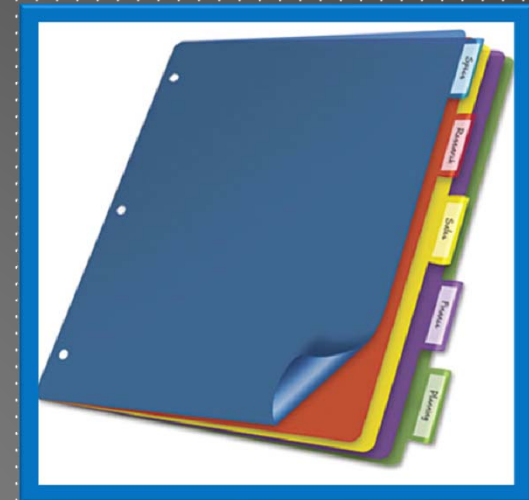




# ORGANIZING THE MEDICAL NOTEBOOK

## Tab 1: Cardiology

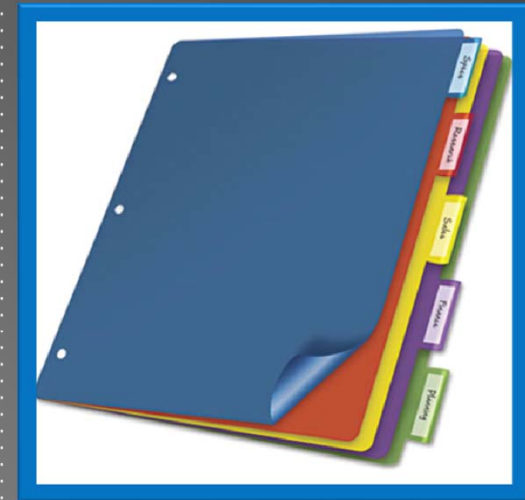
- Doctor's name
- Medications
  - All the medications you have tried
  - Dosages that were prescribed
  - Levels that were obtained
  - What has worked and what hasn't worked
  - Why it was discontinued
- Imaging (specific to that specialty)
- Labs (specific to that specialty)
- Progress notes



# ORGANIZING THE MEDICAL NOTEBOOK

## Tab 2: Gastroenterology

- Doctor's name
- Medications
  - All the medications you have tried
  - Dosages that were prescribed
  - Levels that were obtained
  - What has worked and what hasn't worked
  - Why it was discontinued
- Imaging (specific to that specialty)
- Labs (specific to that specialty)
- Progress notes



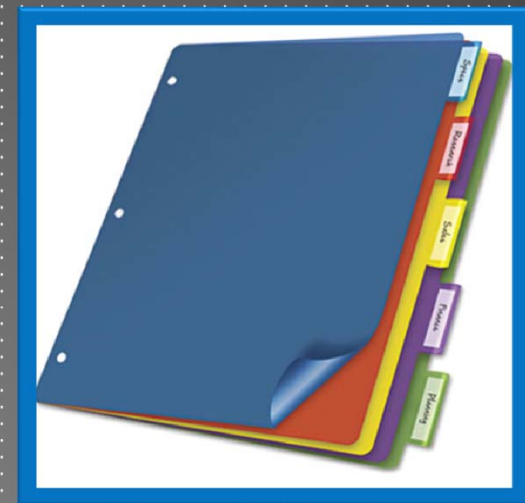
# ORGANIZING THE MEDICAL NOTEBOOK

Tab 3: Endocrinology

Tab 4: Neurology

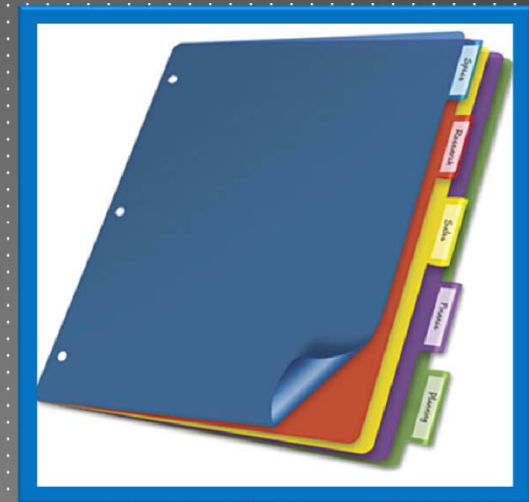
Tab 5: Pulmonology

Tab 6: Hematology



# ORGANIZING THE MEDICAL NOTEBOOK

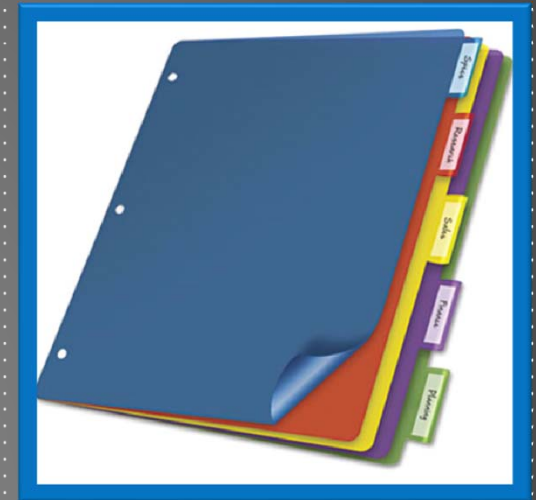
- **Tab 7: Additional imaging that may not fit any specialty**
  - ▶ e.g. an ED visit that resulted in an X-ray
- **Tab 8: Special labs**
  - ▶ Biopsies, genetic testing, etc.
- **Tab 9: Equipment**
- **Tab 10: Supplies (vendor)**
- **Tab 11: Pharmacy**





# ORGANIZING THE MEDICAL NOTEBOOK

- Tab 12: School
- Tab 13: Insurance information
- Tab 14: Therapists



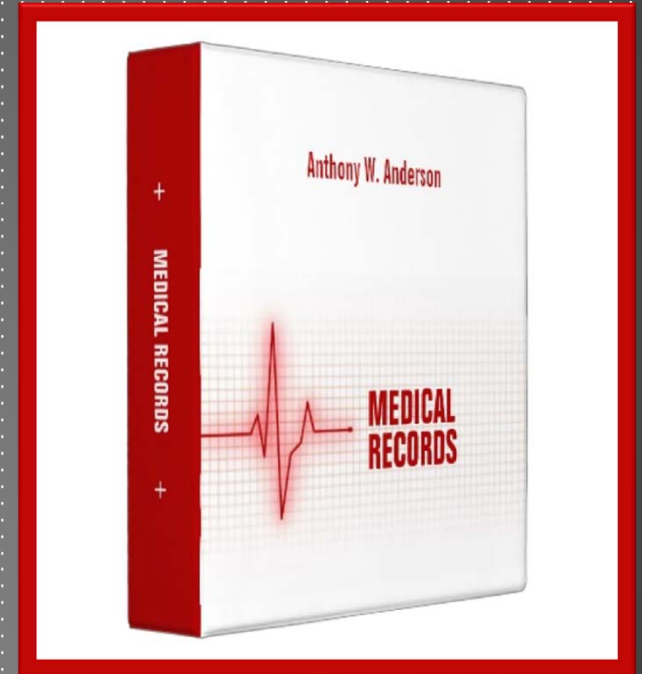
# EDIT YOUR BINDER PERIODICALLY

- Edit to reflect what is currently going on with the child
- If you are unsure of what is necessary, ask the specialist or pediatrician

# ORGANIZING YOUR NOTEBOOK

## 1<sup>ST</sup> PAGE OF NOTEBOOK

- This page can be given to any physician's office to photocopy for the first visit
- List of diagnosis/diagnoses
- List all current medications – doses and frequencies



# POLLING QUESTION

When organizing your medical records,  
how often should you update them?



# C. REGULARLY



# TIPS ON HANDLING MEDICAL APPOINTMENTS



# TIPS ON HANDLING MEDICAL APPOINTMENTS

➤ Keep a bag packed for you doctor visit at all times

- Toys
- Phone numbers
- Snacks/Drinks
- Medications





# TIPS ON HANDLING MEDICAL APPOINTMENTS

- Try to leave your other children at home
- If possible, have another adult attend the appointment with you.





# TIPS ON HANDLING MEDICAL APPOINTMENTS

- Write down all the questions you have
- It takes approximately 3 minutes for the doctor to answer every one question you ask
- Always ask the last question that is on your list first.



# TIPS ON HANDLING MEDICAL APPOINTMENTS

- ▶ Use one calendar for everything
- Try to make the first appointment of the day or the first appointment after lunch
- Leave ample time for parking



# TIPS ON HANDLING MEDICAL APPOINTMENTS

- If the visit doesn't go well with the child –
- Ask if it is ok to make the appointment without the child to have your questions answered





# CHECK IN

Think about 3 things that could help you at you next medical appointment





# WHAT IF YOU ARE UNHAPPY WITH YOUR PHYSICIAN?

- Ask friends and relatives for recommendations
- If moving, ask if current physician can refer you to someone in your new community
- Ask your insurance company
- If you are looking for an expert in the field, perform a Pubmed search on your child's diagnosis.



# STAFF DIFFICULTIES

- Many times the physician do not know about staff that are being difficult to patients
- Be reasonable—if you really feel that someone is being inappropriate, speak with your physician
- If you are having difficulty over the phone, ask to speak with the physician



# “MY CHART”

## ▶ Secure Online Health Connection

- Communicate with your doctor
- For you and all of your family member's – one week before your child turns 12, they will need to sign a release allowing you access to their online records
- If your child has a developmental disability, eligibility documentation, NOD will need to be given in order for you to gain access
- <https://mychart.urmc.rochester.edu/MyChart/>



URMC MyChart - Login Page - Mozilla Firefox

File Edit View History Bookmarks Tools Help

receptionist yelling at patient clipart -... x URMC MyChart - Login Page x +

https://mychart.urmc.rochester.edu/MyChart/ Ask.com

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Sign In

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[Help & Support](#)

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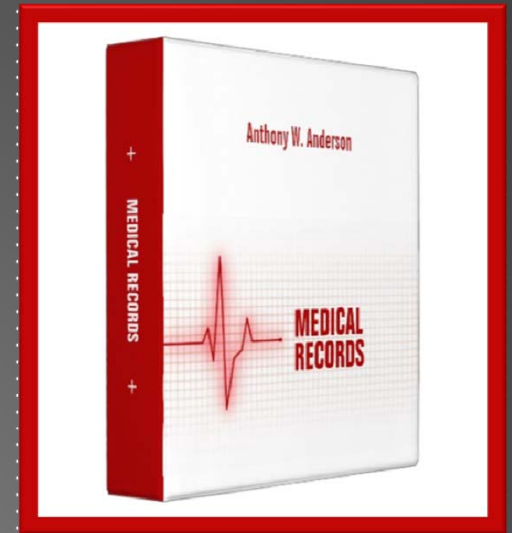
# HELPFUL HINTS: FROM FIRST RESPONDERS AND FIREFIGHTERS

- ▶ Medical background- last visit to the doctors
- ▶ Child's Name
- ▶ Date of birth
- ▶ Mobility level
- ▶ Updated information
- ▶ What comforts the child?
- ▶ Ask for first responders to come to your child's school
- ▶ Visit your local fire department
- ▶ EMS\*Alert on the front doors
- ❖ Notifies First Responders to look on refrigerator for medical information

**EMT\*ALERT**

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Any Questions?

