



**CdLS Foundation**  
Cornelia de Lange Syndrome Foundation, Inc.

# **Welcome to Our Rare Disease Day Health Care Notebook Webinar**



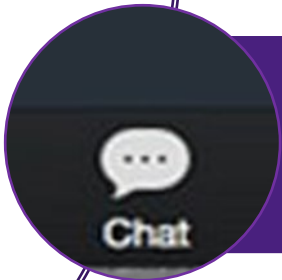
# **ZOOM HOUSEKEEPING**



This webinar is being recorded. If needed, change your name in the participant list.



Participants will not be on camera and will be muted throughout the webinar.



Have questions? Write them in the **CHAT** box. Q and A will follow the presentation.



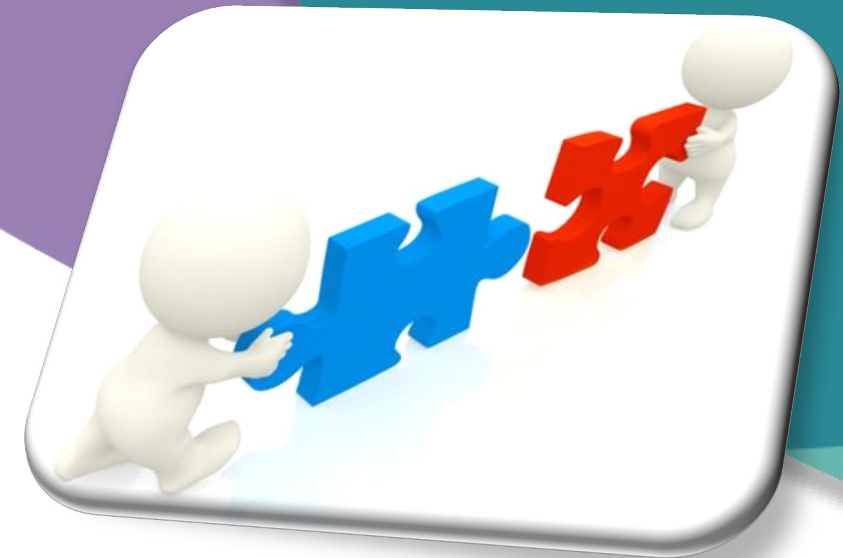
This webinar and The Health Care Notebook will be available on the CdLSusa.org website shortly.

# **Introducing the CdLS Health Care Notebook**

**February 28, 2023**

**Linda Pierce, MSW, Program Director Family Services**

**CdLS Foundation**





# WHAT IS A HEALTH CARE NOTEBOOK?



- A personalized organizational tool
- A centralized place to keep
  - ✓ Information about CdLS especially for new providers or caregivers
  - ✓ Resources to help you navigate/advocate in a medical setting
  - ✓ Important information about your household
  - ✓ Important information about your family member with CdLS
- Can be used either in electronic or print format, or a combination of both!



# WHY HAVE A HEALTH CARE NOTEBOOK?

1) It can seem like a full-time job to keep track of

✓ Appointments	✓ Doctors' names/specialties
✓ Therapies	✓ Test Results
✓ Companies You Deal With	✓ School Personnel
✓ Medications	✓ Questions you want answered



2) We have multiple sources of information

3) We want to find what we need **WHEN** we need it

4) We need an easy way to share certain information with specific people

5) We all benefit from resources and reminders to help us navigate and advocate in a medical setting



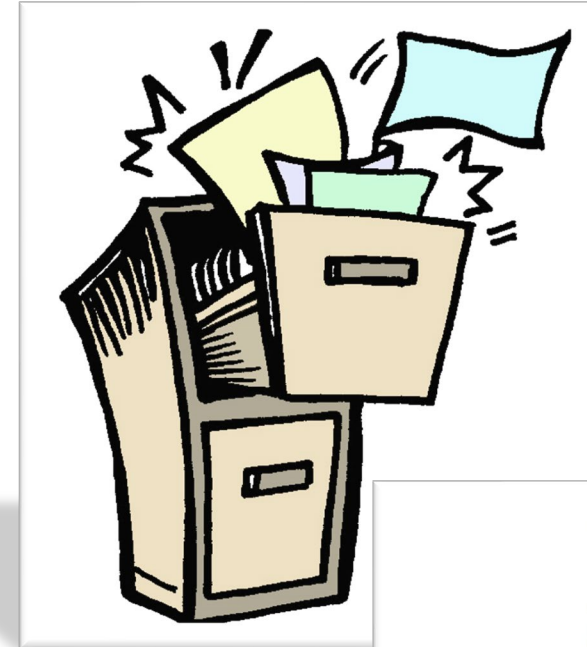
# **GETTING STARTED:** **CREATE YOUR HEALTH CARE NOTEBOOK**

## **1. Gather information you have including:**

- ✓ *Contact information of your care team*
- ✓ *Current medications*
- ✓ *Medical equipment and supplies*
- ✓ *Summaries from recent ER visits, hospital stays or procedures*
- ✓ *Contact information for school personnel*

## **2. If you do not have it already, download the free version of Adobe Reader on your computer.**

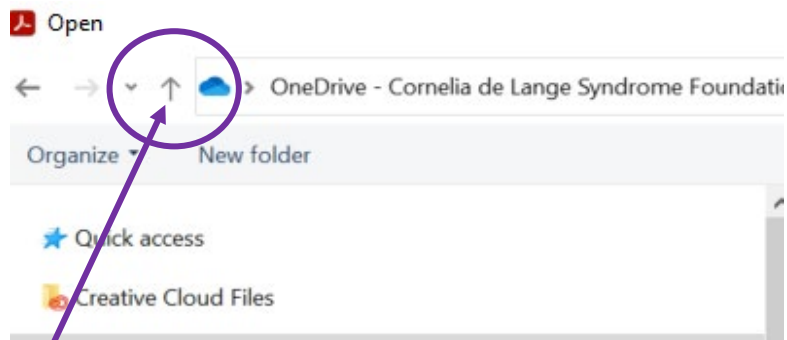
- ✓ *For a computer: <https://adobe.ly/>*
- ✓ *For mobile devices: locate Adobe Acrobat Reader on the App or Google Play Store*





# CREATE A FOLDER: A PLACE TO SAVE YOUR HEALTH CARE NOTEBOOK

## 1) Create a folder to save the Health Care Notebook

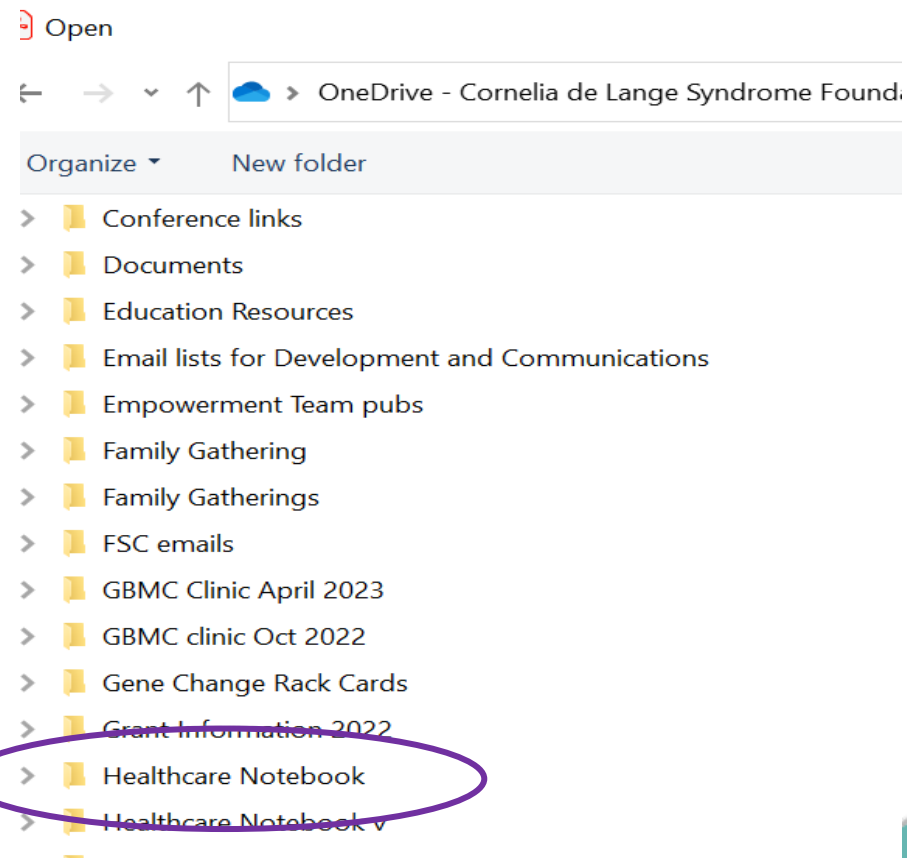


Click on the arrow

## 2) Right-click on New Folder and name the folder



## 3) Your Health Care Notebook has a home!







# DOWNLOAD THE HEALTH CARE NOTEBOOK

[www.cdlsusa.org/healthcare/](http://www.cdlsusa.org/healthcare/)

**CdLS Foundation**  
Cornelia de Lange Syndrome Foundation, Inc.

WHAT IS CdLS? ▾ WHO WE ARE ▾ WHO WE HELP ▾ GET INVOLVED ▾ CONTACT US ▾ **DONATE**

## Navigating Health Care Systems

Ensuring your loved one with CdLS gets the care they need can seem like a full-time job. There are multiple care systems to understand, and it can quickly become confusing. This page is here to help you navigate.

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**CdLS Health Care Notebook**

The CdLS Health Care Notebook is the first of multiple tools from the CdLS Foundation that makes accessing and coordinating care more manageable. It provides an easy way to keep track of important information so you can find it and share it any time you need. You can update the notebook in real-time, with the ease of a smartphone or any electronic device.

**DOWNLOAD NOW**

1 / 26 | - 80% + | [Icons]

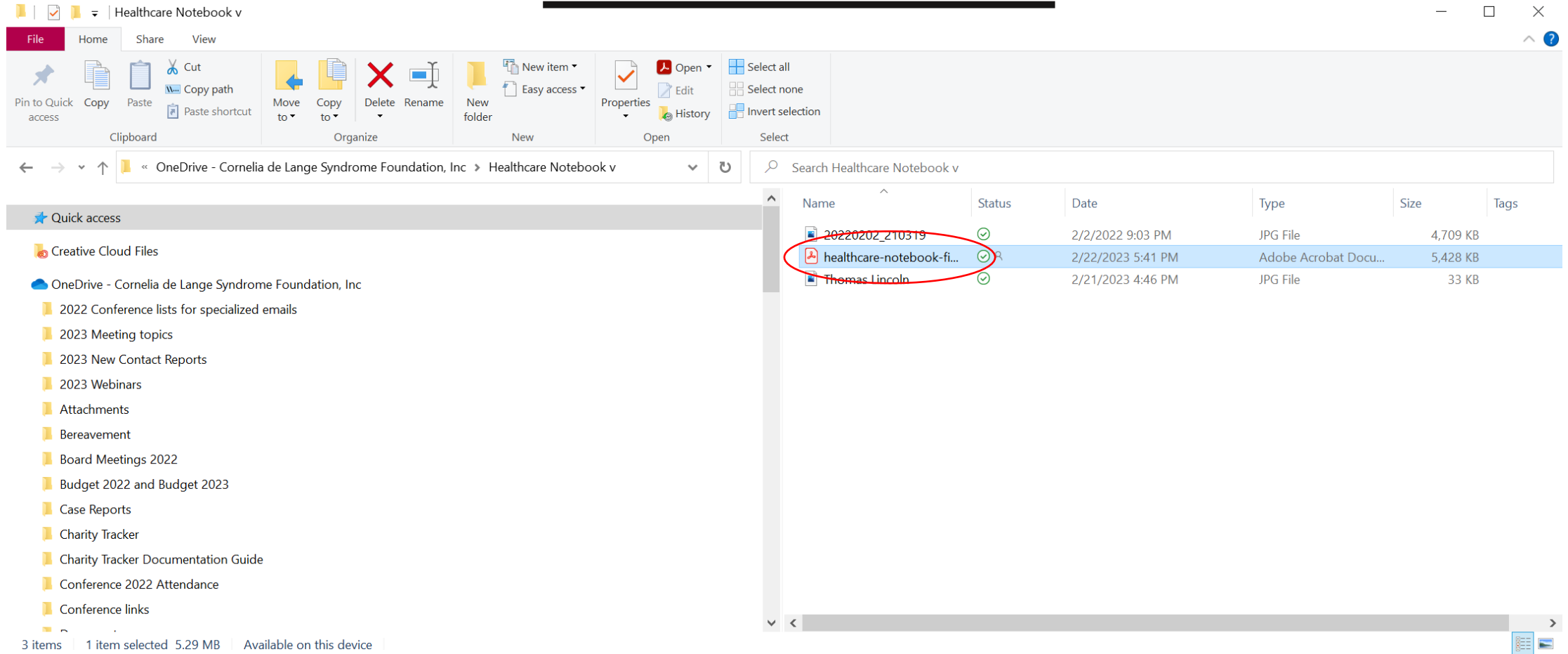
## CdLS HEALTH CARE NOTEBOOK

for families of individuals with CdLS

[Download icon]



# SAVE THE NOTEBOOK TO THE FOLDER YOU CREATED\*



**\*MAC Users: Download to your download folder and then move to a Health Care Notebook folder.**

# WHAT'S INSIDE THE HEALTH CARE NOTEBOOK?

## TABLE OF CONTENTS

03	💡	ABOUT YOUR HEALTH CARE NOTEBOOK
04	👤	PERSONAL INFORMATION
06	🚑	IMPORTANT/ EMERGENCY CONTACT INFORMATION
08	💊	MY PHARMACY
09	🏥	PREPARING FOR A HOSPITAL STAY
13	👨⚕️	DOCTOR INFORMATION
16	🩺	MEDICAL EQUIPMENT AND SUPPLIES
17	🎓	MY SCHOOL
18	🏞️	MY RECREATION AND LEISURE ACTIVITIES
19	👨👩👧👦	FAMILY SUPPORT RESOURCES
20	📅	CHARTS AND LOGS
22	📅	PLANNING FOR WHEN YOUR CHILD TURNS 18
24	📊	ADDITIONAL RESOURCES

Resource material to review.

Fill out these forms.

**Pro Tip:**  
Fill out forms on the largest screen you have. Then, move the Health Care Notebook to documents on your phone.



# HOW CAN I BEST USE THE CdLS HEALTH CARE NOTEBOOK?

- Treat your Health Care Notebook as a one-stop shop for essential information.
- Add information about CdLS to your Health Care Notebook folder
  - Gene Brochure\*
  - Dear Provider letter\*
  - Ask The Expert Card\*
- Keep copies of important legal documents like guardianship with your Health Care Notebook.
- Save information like test/scan results with your Health Care Notebook
- **Make sure your Health Care Notebook is with you at all visits (hard copy or electronic)**
- **Update your Health Care notebook as information changes**
- **Share your ideas to improve the Health Care Notebook with us**



***\*Contact us for copies of this information in electronic or print format.***

For questions after the webinar email  
**[FamilyserVICeSteam@CdLSusa.org](mailto:FamilyserVICeSteam@CdLSusa.org)**  
or call 1.800.753.2357, press 1.



Download the Health Care Notebook  
**[www.cdlsusa.org/healthcare/](http://www.cdlsusa.org/healthcare/)**