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## ***FIRST 100 DAY JOURNEY WITH CLS***

### ***A GUIDE TO NAVIGATING LIFE WITH COFFIN-LOWRY SYNDROME***

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The *First 100 Day Journey with CLS* is a guide created by CLS parents and caregivers who have walked this path before you, to help you navigate this new diagnosis.

A Coffin-Lowry Syndrome (CLS) diagnosis is not the end, but rather the beginning of a journey down a new pathway. You may feel overwhelmed - we are here to help and provide you with resources, care and support in the days, months and years ahead. Give yourself time as you are processing the road that lies ahead; but, be assured that **you are not alone**.

The mission of the CLS Foundation is to provide information and support for families, caregivers, relatives, educators and medical professionals involved with individuals diagnosed with Coffin-Lowry Syndrome, with a focus on family support.

The list below is a tool to help you think about steps you can take to find the resources available to help your child thrive. Please visit our website at [www.coffinlowry.org](http://www.coffinlowry.org) to start exploring what to expect as well as ways to engage with the CLS Foundation and the CLS community. If you have questions, please reach out and contact the CLS Foundation at any time. We are here for you, providing the support your family needs and hopeful for a promising future.

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## ***30 DAYS***

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### **Family and Community**

- Share your diagnosis.
- Surround yourself with supportive, positive people.



- Connect with your own feelings.
- Talk regularly with your spouse, children, and family members to connect with their feelings.
- Suggest ways family and friends can help. They want to, but don't always know how to ask.
- Connect with other families who are experiencing the same journey as you. Our website [www.coffinlowry.org](http://www.coffinlowry.org) can connect you with families directly or online through our private Facebook group. [Join now](#) and connect with others like you in our online community of families impacted by CLS to seek and provide support, ask questions, find resources, and learn how to advocate for your loved one with CLS.
- Sign up for the [New Parent Registry](#).  
Your contact information is not shared with anyone outside of the CLS community without your express permission.
- Take care of yourself. Get enough sleep and rest. Exercise helps to keep your mind clear and make sure you are eating nutritious foods your body needs. The caregiver needs care.

### Record Keeping

- Create a binder or other method to help you organize records, tests, reports, contacts, etc. Update as new information becomes available.
- Prioritize your child's challenges (i.e. communication, fine motor, gross motor, sleep, eating/drinking/nutrition and growth).
- Create a log book to track progress and regression.
- Create a video record of any unusual behavior to show your physician.

### Services

- For children younger than three years of age, contact your Department of Health or government agency to see what services are available to you. In the United States, you should contact your state for Early Intervention (EI) services.
- For children older than three years of age, specialized services will be provided by your school system. In the United States, you will receive an Individualized Education Plan (IEP) tailored for your child. This varies by state.



- Contact the Social Security Administration to see if your family qualifies for Supplement Security Income (SSI) and Medicaid services ([www.sss.gov/register/who-needs-to-register/](http://www.sss.gov/register/who-needs-to-register/)).
- If your loved one is diagnosed as an adult (no longer in the school system) consult with local agencies on services provided to adults with disabilities. They should be able to help you navigate forward.
- In the United States, some states offer day care for your child up to age 12. Research day care/child care/sitter options for assistance in caring for your child.
- In the United States, contact the Social Security Administration to determine if your loved one with CLS qualifies for Supplemental Security Income (SSI).

### Therapy

- What therapy is your child currently receiving? Prioritize your top three concerns today and focus on these (i.e. communication, fine motor, gross motor, sleep, eating/drinking/ nutrition and growth).
- Make an appointment with each therapist to discuss any concerns.

### School

- Make a consultation appointment with your child's Early Interventionists (United States) or school Educators to discuss the learning and development plan now that you have a diagnosis.
- Turning three years old soon? Learn about the education plan at your school system. In the United States, an Individualized Education Plan (IEP) process is developed in your state and school system. (IEPs are specific to the United States. For areas outside the US, contact your local school system.)

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**60 DAYS**

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### Medical

- Schedule appointments with specialists for baseline evaluations and assessments such as a neurologist, cardiac specialist, orthopedic specialist and physical or



occupational therapist. It is not likely that you will find professionals who specialize in CLS, and that's OK.

- Document any changes your child experiences.
- Ask a family member or friend to accompany you to appointments, to help with your child or take notes so you can focus and remember important information.
- Refer professionals to [www.coffinlowry.org](http://www.coffinlowry.org) to help them better understand the diagnosis.
- Consult with your geneticist or genetics counselor for further genetic testing for female family members. See "Genetics of CLS" section of [www.coffinlowry.org](http://www.coffinlowry.org) website for further details.

### **Therapy**

- Schedule a meeting to review and discuss beneficial therapies specific to your child now that your therapist has learned more about CLS.

### **School**

- Keep an open line of communication.
- Provide educators with research of best practices regarding how children with CLS learn and thrive. Suggest they go to [www.coffinlowry.org](http://www.coffinlowry.org) for more information.

### **Insurance**

- Review your insurance coverage regarding which therapies may be covered to ensure you are maximizing your benefits. If a needed therapy is not covered, petition your employer for coverage of the needed therapy.

### **Research**

- Double check with your local Health Department as your child might be entitled to services you were not aware of or had not considered. (This will vary by country and state).
- Waiver Programs as well as additional Federal and State sources are other potential areas of support. (This will vary by country and state.)
- Special Needs Wills and Trusts



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## **90 DAYS**

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### **Family and Community**

- Research activities for individuals with special needs in your area.
- Research a special recreational association in your area with trained staff that provides programs and special events.
- Ask family and friends for help with appointments or therapies. They want to help.
- Find a caregiver or sitter for respite. It is important you get plenty of sleep, rest and exercise.
- Plan to attend a future CLS Family Gathering.

### **Research**

- Research additional therapy options or specialists, such as therapeutic riding, aqua therapy, and more.
- Provide your child's medical history on the Sanford Research CoRDS Registry. CoRDS is a database that gathers health information about individuals with Coffin-Lowry Syndrome to be accessed by researchers and doctors for the advancement of research, future clinical trials and development of potential treatments. [Visit the Patient Enrollment System.](#)
- Attend a CLS Talks quarterly webinar. Additional information can be found on the [www.coffinlowry.org](http://www.coffinlowry.org) website under the Events pages.

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## **NEXT STEPS**

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### **SUGGESTIONS FOR YOUR BINDER**

Use a three-ring binder with tabs including:

- Reports - Include copies of all diagnostic reports, such as your CLS genetic diagnosis or EEGs. Ask for an electronic copy of results.



- Prescriptions - Include a copy of all prescriptions for any medications, specialized equipment and therapies.
- Specialists - Include contact information for all specialists. Specialists may include: Physician/Pediatrician, Neurologist, Cardiologist, Pulmonologist, Orthopedist, ENT, Allergist, Ophthalmologist, Dentist, Orthotist, Physical Therapist, Occupational Therapist, Communication Specialist, and Nutritionist.
- Therapies - Include contact information for all therapists (PT, OT, AAC, etc.). Include their reports and any handouts for exercises.
- Equipment - Include receipts from equipment vendors, notes on how to use equipment and contact information. Know whom to call if equipment breaks.
- Programs - Include information about the programs or organizations in which your child participates.
- Early support plan (Early Intervention (EI) in the United States) - Include documents and therapy reports for children under three years old receiving services related to their limitations.
- Family Support plan for your child (Individualized Family Support Plan (IFSP) in the United States) - Include your child's plan and any related documents for authorized support services such as respite, or personal care supplies.
- Education Plan for your child (This is an Individualized Education Plan (IEP) in the United States) - Include your child's education plan and any documents related to school for children three and older.

#### **OTHER**

- Contact your local Department of Motor Vehicles to apply for an Accessibility (Handicap) Parking Placard if needed. If your child has characteristics that limit their mobility, they should be eligible. You may need your child's doctor's approval on the form.