

Palliative Care



**Children's Hospital**  
New Orleans  
LCMC Health

# Navigating Pediatric Serious Illness:

## Resource Booklet

A guide for families of children, adolescents,  
and young adults living with chronic or serious illness.

# Louisiana State Programs

## Medicaid

All managed healthcare plans under Louisiana Medicaid are accepted by Children's Hospital and by Children's Hospital affiliated providers and clinics.

**For assistance applying for Medicaid for your child, you may contact the Children's Hospital financial aid office at 504.894.6841.**

### **If your child has extra medical needs, they may qualify for Medicaid, regardless of your income.**

- Under the Children's Medicaid Option, or TEFRA Act 421, all children considered to have a disability under the age of 19 are eligible for Medicaid, regardless of the family's financial status. A "disability" is defined using the definition utilized in the Supplemental Security Income program of the Social Security Administration, regardless of whether the child is eligible to receive benefits under that program. Visit [ldh.la.gov/act421](http://ldh.la.gov/act421) for more information.
- Many families with private insurance are able to add Medicaid as a secondary insurance for their child with extra medical needs.

Your child with extra medical needs may also benefit from having a case manager through Medicaid.

- A case manager through your child's managed care plan can act as an advocate for your child within the Medicaid system. They can help ensure that your child has access to all the resources available to them through their insurance plan.
- In order to get an assigned case manager through your Medicaid managed care plan, call the number provided on your child's Medicaid card, and tell Medicaid that you would like to know who your child's case manager is. If they have not been assigned one, ask for them to assign one to your child.



## Office for Citizens With Developmental Disabilities (OCDD)

OCDD provides a variety of services to help support people with developmental disabilities and their families in their homes and communities. These services include therapies, personal care attendants, and equipment. Through your region's human services district office, you can gain access to these support coordination services. Please see the list below to contact your specific region's office and begin the intake process for your child.

### Acadiana Area Human Services District

302 Dulles Drive, Lafayette, LA 70506 | 337.262.5610

### Capital Area Human Services District

4615 Government Street, Building 2, Baton Rouge, LA 70806 | .225.925.1910

### Central Louisiana Human Services District

5411 Coliseum Blvd, Alexandria, LA 71303 | 318.484.2347

### Florida Parishes Human Services Authority

835 Pride Drive - Suite B, Hammond, LA 70401 | 985.543.4730

### Imperial Calcasieu Human Services Authority

One LakeShore Drive, Suite 2000, Lake Charles, LA 70629 | 337.475.3100

### Jefferson Parish Human Services Authority

1500 River Oaks Road West, Suite 200, Jefferson, LA 70123 | 504.838.5424

### Metropolitan Human Services District

3100 Gen de Gaulle Dr, New Orleans, LA 70114 | .504.568.3130

### Northeast Delta Human Services Authority

2513 Ferrand Street, Monroe, LA 71201 | 318.362.3396

### Northwest Louisiana Human Services District

3018 Old Minden Road, Suite 1211, Bossier City, LA 71112 | 318.741.7455

### South Central Louisiana Human Services Authority

158 Regal Row, Houma, LA 70360 | 985.876.8805

## Supplemental Security Income (SSI)

Many children living with serious illness can qualify for social security income (SSI) through the federal Supplemental Security Administration. This assistance is a monthly payment to help cover the additional costs that are often associated with caring for a child with serious illness. In order to qualify, the child must be under the age of 19 and considered to have a disability. The family must also meet income requirements. To learn more about this program and start the application process, please visit the SSA website at [ssa.gov/ssi](https://www.ssa.gov/ssi).

Please note, at this time you may begin your child's application online; however, the whole application cannot be completed online. To complete the application, you must have an appointment with the SSA office. If this has not been arranged online, please call **1.800.772.1213**. For the deaf or hard of hearing, please call TTY **1.800.325.0778**.

## SNAP Benefits/Food Stamps

If you live in a low-income household and you need assistance with purchasing food for your family, you may qualify for the SNAP program, formerly called "food stamps". This program will provide you with a monthly payment on a card that can be used at many food stores. In order to apply, sign up for LA Café through the Department of Children and Family Services (DCFS). Through this portal, there may be other government subsidy programs you can qualify for. Please visit [dcfs.louisiana.gov](https://dcfs.louisiana.gov) for more information and to apply.

## WIC

This is a state-run supplemental nutrition program for Women, Infants and Children (WIC). The program is open to women who are pregnant, breastfeeding or have already delivered. Infants and children up to their fifth birthday may also receive benefits. In some cases, your child may require a specialized formula that they can best tolerate. In order to communicate this information to the WIC office, you can receive a WIC referral from your child's assigned hospital dietician. To learn more, locate your local WIC office, and even apply online, go to the Louisiana Website listed below. [louisianawic.org](https://louisianawic.org)

## Health and Development Support Programs

### Home Health & Pediatric Medical Daycare

There are several options for help with your child's extra medical needs outside of the hospital. One option is called home health extended nursing. A registered nurse can come to your house to care for your child and their medical needs for hours per day. A second option is called pediatric medical daycare. This facility operates as a daycare for children with extra medical needs who may not be able to be properly cared for at a regular daycare or school. It is staffed by trained medical personnel including nurses and therapists. Unfortunately, at this time, pediatric medical daycares are only available to people with Medicaid. In many cases, there are waitlists for one or both options, and neither is a guaranteed benefit.

To learn more about your specific options for these two services, ask your medical team to consult case management. Your hospital case manager can fully review your options with you and make necessary referrals. If your child is not in the hospital and you would like to learn more about these options, please contact your child's primary care pediatrician.

### Early Steps

Early Steps is a government-funded program that allows children to receive therapies to assist in their development at home. If qualified, the Early Steps program will provide physical therapy, occupational therapy, speech therapy, and case management in the home at no cost to the family. This program lasts until age 3, at which time your Early Steps coordinator will help your child transition to the public school system for their therapies.

To learn more about Early Steps or for a referral, ask your medical team to consult social services. If your child is not in the hospital and you are interested in a referral, please contact your child's primary care pediatrician.

## Education and Advocacy Support Programs

### Families Helping Families

This organization is a family directed resource center serving the entire state of Louisiana. They provide peer to peer support, information, resources, and training on disability/special health care needs and special education topics. They have ten family resource centers located throughout Louisiana. [fhfogn.org](http://fhfogn.org)

### Courageous Parents Network

This network is an online destination created by parents, for parents, to support, guide and strengthen families as they care for a seriously ill child. Here you will find wisdom from fellow parents and pediatric care providers to help you be the best parent you can be to your child and children—and get through each moment. [courageousparentsnetwork.org](http://courageousparentsnetwork.org)

### Saul's Light

This organization provides support to families with babies who are being treated in the NICU. They can offer financial support to help families visit their babies in the hospital as well as peer to peer support. [saulslight.org](http://saulslight.org)

### Caring Bridge

At times support from family and friends can feel overwhelming. Communicating information to them while also focusing on your child's health can inadvertently contribute to your stress. CaringBridge is a free online tool for sharing health updates and provides an easy way to communicate health news to family and friends all in one place. [caringbridge.org](http://caringbridge.org)

## Financial Support Programs

### Chive Charities

This organization provides grants for individuals with life-altering or life-threatening needs. From therapy equipment like adaptive tricycles and robotic walkers to service dogs, wheelchair-accessible vans, and a wide range of mobility items, Chive Charities fills the gaps where insurance and other resources cannot. For more information and assistance in applying for this grant, please contact your social worker or the Pelican Krewe. [chivecharities.org](http://chivecharities.org)

### Cerner Charitable Foundation

This foundation provides individual medical grants that cover a wide variety of clinical, equipment, travel & lodging, and vehicle modification costs related to children's healthcare needs. There are financial eligibility requirements. Please ask your social worker or the Pelican Krewe for more information and assistance applying for these grants. [cernercharitablefoundation.org](http://cernercharitablefoundation.org)



## Quality of Life Support Programs

### Wish Granting Organizations

Any child diagnosed with a life-limiting or life-threatening illness, between the ages 2 and 18, is eligible for a "wish." Once referred by your hospital social worker, your child may participate in their wish at any time during or soon after their treatment, if it is medically safe and approved by your physician. Your child is eligible for one wish. Below please find the three Wish organizations. Please choose one and your social worker or the Pelican Krewe will assist with your child's referral.

#### A Child's Wish

Only Louisiana residents are eligible.  
[achildswish.org](http://achildswish.org)

#### Dreams Come True of LA

Only Louisiana residents are eligible.  
[dctofla.com](http://dctofla.com)

#### The Make A Wish Foundation

[texgulf.wish.org](http://texgulf.wish.org)

### Icing Smiles

This is a national program offering custom made cakes for children with serious illness and their siblings. Get a custom-made cake for your child's birthday or other special event. Please note, you must start the referral process at least four weeks prior to your special event. [icingsmiles.org](http://icingsmiles.org)

### Audubon Institute of the Americas

Our hospital is fortunate to be in the same city as an amazing aquarium and right next door to a spectacular zoo! Families often enjoy visiting one of these attractions when they are in town for a clinic visit, or when siblings are in town to visit their brother or sister in the hospital. Any family receiving services from the Pelican Krewe is eligible for free tickets once per year to the Audubon Zoo or Aquarium. If you are interested in tickets, please contact your social worker or the Pelican Krewe.



**Children's Hospital New Orleans**  
**Pelican Krewe**  
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