

# Community Resources for the Child with Sickle Cell Disease

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# Psychosocial Issues

- Compliance
- Chronic Illness
- Frequent Visits
- Employment Issues



# Information

- [www.SickleCellKids.org](http://www.SickleCellKids.org)
  - an interactive child friendly educational website
- [www.sicklecelldisease.org](http://www.sicklecelldisease.org)
  - addresses issues related to Sickle Cell Disease and has a list of links and resources
- [www.marow.org](http://www.marow.org)
  - National Marrow Donor Association
    - information on transplant process



# Caregiver Resources

## Family Medical Leave Act (FMLA)

- A federal act which requires employers to grant an eligible employee up to a total of 12 work weeks of unpaid leave during any 12-month period for qualified reasons.
- Does not apply to all employers



# Financial Resources

## Supplemental Security Income (SSI)

- Disability for children
- [www.ssa.gov](http://www.ssa.gov) or 800-772-1213
- Eligibility criteria include: low income, disease results in marked and severe functional limitations, can be expected to result in death, has lasted or can be expected to last for a continuous period of not less than 12 months.

## Medicaid's Medical Transportation Program (MTP)

- 877-633-8747
- Financial assistance with transportation for medical appointments and meal money and lodging costs for out-of-town patients



# Financial Resources

## Project Joy and Hope

- local housing resource to help with housing costs if the 'child's critical illness is impacting the family economically'
- Funded by a grant through The City of Houston
- [www.joyandhope.org](http://www.joyandhope.org)

## United Way – 211

- Information about every health and social service available in the community
- [www.unitedwayhouston.org](http://www.unitedwayhouston.org) or dial: 211

## The Bone Marrow Foundation

- The Patient Aid Program – one time financial assistance – average grant amount is \$500; 8 – 10 week processing time
- [www.bonemarrow.org](http://www.bonemarrow.org)

## MD Anderson Resources



# Support Services

## Make-A-Wish Foundation

- [www.wish.org](http://www.wish.org)
- not all patients qualify
- patients must meet medical criteria which consists of organ impairment or life threatening complication