Help for Families of Children with Birth Defects

If you have a child that was born with a birth defect, there are resources that can help your family.

If you need help with paying for medical care and meet the income requirements, these programs can help:

- Medicaid: Healthsource RI - 855-840-4774 or https://healthsourceri.com/
- Supplemental Security Income (based on parent’s income): 800-772-1213
- Katie Beckett (based on child’s income): 401-462-0633

If you need to talk to other parents, these support groups can help:

- Peer to Peer Connections at the Rhode Island Parent Information Network (RIPIN): 401-270-1010, x139
- Down Syndrome Society: 401-463-5751
- Spina Bifida Association of Greater New England: 888-479-1900
- The Rhode Island School for the Deaf: 401-222-3525

Online (internet) support groups for parents of children with specific conditions are also available:

- Heart defects: https://mendedhearts.org/about-us/
- Craniostenosis: craniocarebears.org
- Cleft lip/palate: https://acpa-cpf.org
- Gastrochisis: averysangels.org
- Hearing loss supports: http://www.cdhh.ri.gov/

There are community organizations that can help you too:

- First Connections: A Rhode Island Department of Health home visiting program that can help connect families to services: http://health.ri.gov/find/services/detail.php?id=34
- Visiting Nurse Association: http://www.health.ri.gov/healthcare/providers/homehealthagencies/
- RIPIN: help with healthcare, education, support groups, referrals: RIPIN.org or 401-270-0101
- RIREACH: help with healthcare questions: 855-747-3224

If you need help with education and development services, you can contact:

- Early Intervention: helps families support the growth and development of the child, birth to age three, who is delayed or has a medical condition known to cause delays: http://www.eohhs.ri.gov/Consumer/FamilieswithChildren/EarlyIntervention.aspx
- Children’s Neurodevelopment Center: 401-444-3500
- Cedar Family Centers (Medicaid requirement): RIPIN 401-270-0101 or Three Cedar 401-444-7703
- Special Education or Individual Education Plan (IEP): your local school department

Learn about other places that can help you. Visit RIBDP web page at:

- www.health.ri.gov/programs/birthdefects/