



# R.C.P.U. NEWSLETTER

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R.C. Philips Research and Education Unit

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A statewide commitment to the problems of mental retardation

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## Coping with a new diagnosis

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### The Diagnosis:

Learning that their child has a medical condition or developmental problem can give parents a feeling of their world being turned upside down. Everything in their life may suddenly feel out of control. This is because they did not choose for their child to have a problem. Their initial thoughts may be "How could this have happened to my child?" and "How will we get through this?"

A medical or developmental diagnosis is shocking and overwhelming. However, in order to be of assistance to your child, you must be able to move forward and to evaluate what your options are, and where help is going to come from.

Some practical things that you can do to help during this time include the following:

1. Learn as much as possible about your child's condition. Lack of knowledge can be your worst enemy. Arm yourself with information and do not hesitate to ask questions. You may wish to keep a notebook with all of the medical records and information about your child's diagnosis.
2. Keep a journal of your feelings about your child's condition and the impact on your life. As time goes on, you will be able to look back and see that things are improving and that you are moving forward, even though at times it may not seem so.
3. Learn about your health benefits so that you understand what expenses will be covered by insurance. Explore the options that are available to assist you through State or Federal programs.
4. Continue doing your usual daily activities. "Routine" activities can help you cope and feel more in control.
5. Take care of your family relationships. Although your primary focus is on your child, it is important to also spend time as you normally would with your other children and your spouse. It is healthy to have fun together, even when a child in the family is ill. Relieving stress and strengthening family relationships will allow you all to cope better with your child's disease.
6. Utilize the support groups in the area, as well as national support groups and their resources. Find out about supportive services available at the hospital to help you cope, such as the availability of social workers and/or meeting with other families. Do not be afraid to

ask for help. Each family's need for support is unique. Friends and family members will often ask "Is there anything I can do to help?" Consider saying "yes" to this question and ask them to pick up your groceries, help with the laundry or housecleaning, pick up your other children from their extracurricular activities, or make dinner. "Assigning" a friend or family member something to do to help you will also help them feel like they are contributing.

7. Sometimes, well-meaning friends and family members will say the worst possible thing at the time of a difficult diagnosis. They truly want to help or be supportive, but sometimes do not know how to respond. Their words may hurt you or disappoint you, even though that was not their intention. You must realize that people will not know what your needs are unless you tell them. Sometimes, it is simply easier to be forthright and tell someone "I would just like you to sit quietly with me and keep me company" or "I need to spend some time alone right now." Do not be afraid to express your needs. Other parents or acquaintances may want to talk to you about their experiences with their children. They may believe that they are being helpful to you, but instead may be making your situation feel even more overwhelming. It is important for you to avoid these discussions if they are not helping you. It is healthy to be "selfish" and ask for what you need, as well as what you do not need during this time.
8. Share what you have learned. You will have important knowledge and skills that you learn as you experience your child's condition. You could help other parents and their families by sharing your experiences in a support group or other setting.

### State Resources:

There are multiple avenues to seek assistance for children and families with children with medical or developmental disorders, but it is sometimes difficult for parents to identify these resources. In this newsletter, we will discuss some of the resources available.

### A. Centers for Autism and Related Disabilities (CARD):

Autism and autism spectrum disorders (ASD) are being diagnosed with increased frequency in our population. The CARD centers were founded in

order to assist families in finding appropriate resources for their children with autism/ASD.

CARD is founded on the strong belief that:

1. All individuals, regardless of their abilities or disabilities, have the right to live as full participants in society.
2. All people have the right to be treated with dignity and understanding.
3. People with disabilities are members of families. All families have strengths and capacities and have the right to be treated with sensitivity and respect, and as integral members of a person's system of support.
4. People with autism and related disabilities have the right to be regarded as individuals who need services and supports that are based on their unique characteristics.

The incidence of autism spectrum disorders is increasing and it affects many individuals and families in Florida. In response to the needs of these people, seven nonresidential resource centers have been established. Each center has its own structure and is responsible for serving children in the surrounding counties. The centers are:

**Florida State University – Tallahassee** (850) 644-4367.

Website: <http://autism.fsu.edu/>

Counties serviced include: Escambia, Santa Rosa, Okaloosa, Walton, Holmes, Washington, Bay, Gulf, Jackson, Calhoun, Gadsden, Liberty, Franklin, Leon, Wakulla, Jefferson, Madison, and Taylor.

**University of Florida – Gainesville** (800) 9-autism

352-273-0581 Website: <http://card.ufl.edu/>

Counties serviced include: Hamilton, Suwannee, Lafayette, Dixie, Columbia, Gilchrist, Levy, Union, Alachua, Bradford, Putnam, Marion, Citrus, Hernando.

**University of Florida – Jacksonville** (904) 633-0760 or (800) 928-8476.

Website: <http://www.hscj.ufl.edu/pediatrics/autism/>

Counties serviced include: Baker, Clay, Nassau, Duval, St. John's, Flagler.

**University of Central Florida – Orlando** (407) 823-6011.

Website: <http://ucf-card.org/>

Counties serviced include: Sumter, Lake, Volusia, Seminole, Orange, Osceola, Brevard.

**Florida Atlantic University – Boca Raton** (561) 297-2023.

Website: [www.coe.fau.edu/card](http://www.coe.fau.edu/card)

Counties serviced include: Indian River, St. Lucie, Martin, Okeechobee, and Palm Beach.

**University of Miami – Miami** (305) 284-6563.

Website: <http://www.umcard.org/>

Counties serviced include: Broward, Dade, and Monroe.

**University of South Florida – Tampa** (813) 974-2532.

Website: <http://card-usf.fmhi.usf.edu/>

Counties serviced include: Pasco, Pinellas, Hillsborough, Polk, Manatee, Hardee, Highlands, Sarasota, DeSoto, Charlotte, Glades, Lee, Hendry, Collier.

CARD works with families, caregivers and professionals to optimize the potential of people with autism and related disabilities. There are seven non-residential CARD centers across the state. The CARD staff includes professionals with expertise in psychiatry, psychology, special education, nursing, applied behavior analysis, and speech-language pathology. The centers are funded by the Florida legislature, so all of their services are free.

CARD serves children and adults of all levels of intellectual functioning who have autism, autistic-like disabilities, pervasive developmental disorder, dual sensory impairments (deaf-blindness), or a vision or hearing loss with another disabling condition. They are required by the legislation that created CARD to have documentation of a qualifying diagnosis in order for an individual to receive our services. The diagnosis can be made by a physician, such as a pediatrician, psychiatrist or neurologist, or by a licensed psychologist. In cases where no diagnosis has been made, they encourage parents to call us for information on where they can go for a diagnostic

evaluation.

#### Services offered:

- **Orientation session** with information about our services, an overview of autism and related disabilities, and more.
- **Referrals** for diagnosis, support groups, existing services (i.e. agencies, doctors, therapists, etc.).
- **Information and Training** on a variety of topics including instructional methods, communication, social skills, behavior, home, school and community issues, and adult life issues.
- **Lending library** with books, videos and DVDs on autism and related disabilities
- **Consultation and Materials for Developing Visual Supports** (schedules, communication aides, choice boards, social stories, etc.)
- **Instruction** on how to identify, prioritize, and communicate your child's needs.
- **Consultative services** (short-term) appropriate to home, school, or community upon request.

#### B. Florida & Virgin Islands (FAVI) Deaf-Blind Collaborative:

Website: <http://www.deafblind.ufl.edu/>

FAVI is an outreach Project for Children and Young Adults Who Are Deaf-Blind is based in Gainesville Florida at the University of Florida Health Science Center. They are funded by the US Department of Education, Office of Special Education Programs, and serve the entire State of Florida.

FAVI is committed to promoting the full inclusion and participation of persons with deaf-blindness as active members of their communities. FOP strives to build the capacity of families, schools, districts, and teams by providing training and disseminating information on sensory loss, multiple disabilities, and best practices. FOP supports individuals, families, teams, and communities affected by deaf-blindness.

FAVI believes that:

1. There is no single profile of a student who is deaf-blind
2. Students who are deaf-blind can participate in every activity
3. Students who are deaf-blind communicate in a variety of ways
4. Many people who are deaf-blind can get around their communities independently
5. Students who are deaf-blind can be included in every teaching environment
6. Educational teams are critical
7. Families are key players on those teams

#### C. Children's Medical Services:

Website: <http://www.cms-kids.com/>

**Children's Medical Services** is a collection of special programs for eligible children with special needs. We have a variety of services for expecting moms, newborn babies, infants and toddlers, school-aged children, adolescents and young adults. All services are provided by highly qualified physicians, nurses, social workers and other health care providers around the state. Through our family-centered programs, we make sure your child gets the care he or she needs.

Our specialty programs fall within several categories. Decide which one meets your child's needs and click the link below to find out more information.

**Health Services** - for eligible infants, children, adolescents, and young adults who have on-going physical or behavioral conditions

**Child Protection & Safety** - for infants, children, and adolescents who have been alleged to be abused or neglected

**Child & Family Information** - for families seeking information about parenting, family care and support, and overall well-being of your child

**Early Intervention / Child Development** - for eligible young children whose development is behind their peers and the families of those children

**Newborn Screening** - for expectant parents and parents of newborn babies

## D. CMS – Early Intervention Services:

Website: [http://www.floridahealth.gov/alternatesites/cms-kids/families/early\\_steps/early\\_steps.html](http://www.floridahealth.gov/alternatesites/cms-kids/families/early_steps/early_steps.html)

Early Steps is Florida's early intervention system that offers services to eligible infants and toddlers (birth to thirty-six months) with significant delays or a condition likely to result in a developmental delay. Early Intervention is provided to support families and caregivers in developing the competence and confidence to help their child learn and develop.

Early Steps services are based on Early Steps evaluations and your family's concerns, resources, and goals. Early Steps uses a Team Based Primary Service Provider approach which aims to empower each eligible family by providing a comprehensive team of professionals from the beginning of services through transition. The goal is for the family to receive strong support from one person, provide a comprehensive team of professionals from beginning to end, and for the family to have fewer appointments and more time to be a "family." Services are provided to the family and child where they live, learn and play, to enable the family to implement developmentally appropriate learning opportunities during everyday activities and routines. Most services will be early intervention home visits. Click on the link below for a short video that demonstrates and explains early intervention home visits.

For most of these services, there will not be a charge or they will be covered by insurance or Medicaid if applicable. These services are provided by contracted local Early Steps offices across the state of Florida.

### Features of Early Steps:

1. Brings services into the child's life rather than fitting the child into services.
2. Maximizes each child's everyday natural learning opportunities.
3. Enhances each child's development and participation in community life.
4. Provides each child with a consistent team for evaluation and services.
5. Gives families options in service decisions and encourages active partnerships.
6. Provides a primary service provider to work with your family, other caregivers, and the team.

## E. Florida KidCare :

Website: <http://www.floridakidcare.org/>

Through Florida KidCare, the state of Florida offers health insurance for children from birth through age 18, even if one or both parents are working. It includes four different parts. When you apply for the insurance, Florida KidCare will check which part your child may qualify for based on age and family income.

1. **MEDIKIDS**: children ages 1 through 4.
2. **HEALTHY KIDS**: children ages 5 through 18.
3. **CHILDREN'S MEDICAL SERVICES NETWORK**: children birth through 18 who have special health care needs.
4. **MEDICAID**: children birth through 18. A child who has other health insurance may still qualify for Medicaid.

## F. Agency for persons with disabilities (APD):

Website: <http://apd.myflorida.com/>

The Agency for Persons with Disabilities (APD) is an agency separate from the Department of Children and Families, specifically tasked with serving the needs of Floridians with developmental disabilities. The APD works in partnership with local communities and private providers to assist people who have developmental disabilities and their families. APD also provides assistance in identifying the needs of people with developmental disabilities for supports and services.

### Agency Goals

The Agency for Persons with Disabilities works in partnership with local communities to support people with developmental disabilities in living, learning, and working in their communities. APD provides critical services and supports for customers with developmental disabilities so they can reach their full potential. The agency serves people with spina bifida, autism, cerebral palsy, Prader-Willi syndrome, and mental retardation. There is no charge or co-payment for services provided through the agency.

### Eligibility

A person must live in Florida, be at least three years old, and have a developmental disability that occurred before the age of 18 to be eligible for APD services. Children ages three to five who are at risk of being diagnosed with a developmental disability may also be served by APD. APD may provide a free assessment to determine if someone is eligible for services.

### Programs

APD customers may be served in their community by funding provided through several waiver programs. Other customers are provided assistance without being enrolled in a waiver program. Some APD customers are served at two Developmental Disability Centers. The agency helps more than 35,000 Floridians with developmental disabilities each year.

### Developmental Disability Centers

Some people with developmental disabilities prefer to receive services and supports living in a home with other people with similar disabilities. The state of Florida has two centers: Sunland Center in Marianna and Tacachale Center in Gainesville. About 700 people currently live in these facilities.

In addition, the agency serves people found incompetent to go to trial due to their developmental disabilities. These individuals are served at APD centers and at a facility located in Chattahoochee. About 200 people live in these locations.

## Non-State Resources:

### A. March of Dimes:

Website: <http://www.marchofdimes.com/>

The goals of the March of Dimes is to help moms have full-term pregnancies and research the problems that threaten the health of babies.

We're reaching moms with information on having full-term and healthy pregnancies. Professional education and medical resources on topics like premature birth and birth defects, are helping health care providers better support their patients.

### B. Understanding Chromosome Disorders (Unique):

Website: <http://www.rarechromo.org/html/home.asp>

The mission of UNIQUE is to inform, support and alleviate the isolation of anyone affected by a rare chromosome disorder and to raise public awareness.

**Unique Aims:**

To act as an international group, supporting, informing and networking with anyone affected by a rare chromosome disorders and with any interested professionals

To publish a magazine three times each year

To promote awareness of rare chromosome disorders

To link families whose children have similar chromosome disorders, clinical and/or practical problems

To support and promote relevant research projects

To help families participate in relevant research projects

To centralise information, at all times observing the need for total confidentiality

To set up local groups, both physical and virtual, throughout the world for families affected by any rare chromosome disorders so that they can give support and encouragement to each other

To hold regional social gatherings for families in the UK

To develop and maintain a comprehensive computerised database detailing the life-time effects of specific chromosome disorders on affected member

To develop a series of family-friendly information guides on specific rare chromosome disorders as well as practical guides on aspects of daily living

To provide anonymised information about the effects of specific rare chromosome disorders to help clinicians counsel their patients

To hold regular conferences and study days where families and relevant specialists can meet and be informed of the latest medical, technical and practical developments

To liaise and work in co-operation with other relevant support groups and professionals world-wide for the benefit of families and individuals affected by rare chromosome disorders

To ensure that hospitals, doctors, health authorities, genetic clinics and other professionals are aware of the group so that we may have early contact with families where required

To give presentations about rare chromosome disorders and the work of Unique to parents' groups, professionals and the general public

To represent the voice and perspectives of families affected by rare chromosome disorders by participating in professional working groups, advisory boards, committees and conferences worldwide

To raise funds to support the group's activities and produce literature to make others more aware of our children's conditions

The R.C. Philips Unit is a resource for all Floridians interested in the diagnosis, treatment and prevention of mental retardation. Staff members are available for consultation and for educational programs for health.

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**C. University of Florida – Genetics & Metabolism Website:**

Website: <http://www.peds.ufl.edu/divisions/genetics/>

The University of Florida, Division of Pediatric Genetics and Metabolism has produced a number of helpful resources on a variety of topics from individual genetic syndromes, to issues of newborn screening for metabolic disorders and hearing screening. The division is home to 3 genetic counselors, 2 metabolic nutritionists and 3 clinical geneticists who can be of assistance in identifying further information on genetics-related issues.

**About the RCPU**

The Raymond C. Philips Research and Education Unit began in 1978 when the legislature established section 393.20, F.S., of what is now known as the "prevention" legislation. It is named after Raymond C. Philips, who was the Superintendent of Gainesville's Tacachale (formerly Sunland) Center for 38 years, and was an acknowledged state and national leader in services for mentally retarded persons. The Unit is located on the Tacachale campus and is funded through a contract with the Department of Children and Families and the Department of Health.

The purpose of the R.C.P.U. is to treat, prevent, and/or ameliorate mental retardation through medical evaluations, education and research. The unit provides direct evaluations and counseling to families and promotes service, education, and prevention projects.

Some of the conditions currently under study at the RCPU involve Angelman, Velo-Cardio-Facial, Prader-Willi, Fragile X, Williams and Smith-Lemli-Opitz syndromes.

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