

Insurance

The cost of health care has skyrocketed to crisis dimensions in recent years, and paying for health care is an additional burden to families of children with special needs. For many people, obtaining insurance coverage is difficult, if not impossible. Once obtained, the insurance may not pay for all of the child's needs. Others may find their policies dropped when they move to a new job or have their child's special needs deemed "pre-existing," and ineligible for coverage.

Types of Insurance

There are a number of different types of insurance protection available. Sometimes the decision is made by your employer, and sometimes you have a choice in selecting healthcare coverage. Often, the type of insurance available is a variation or combination of the following.

- Basic Protection
- Major Medical
- Comprehensive Medical
- Disability Insurance
- Supplemental Policies

Additional Policies

- Minimum Pediatric Life Insurance: from infancy to seven years of age, available without physical exam. This type of insurance is helpful for those who have a family incidence of more than one with Rett syndrome.
- Hospitalization Income Supplemental Plans: provide a payment for every day spent in the hospital. This may not be economical, but may be helpful when frequent hospitalizations are necessary. Often, there is a one-to-two year waiting period to fulfill pre-existing condition qualifications.

Private Insurance Options

- Group Plans: costs are shared by the insured and employers
- Preferred Provider Organizations (PPOs): services are provided with specific health providers, with an option to see nonparticipating doctors at a higher per visit cost.
- Self-Insured Programs: businesses pay all or part of the medical expenses without using insurance. These programs are not subject to state regulation and have very limited legal protection.
- Health Maintenance Organizations (HMOs): groups subscribe to these plans, which provide preventive, ongoing, and hospital coverage, usually with a set fee for service. These plans require that physicians who are members of the HMO are used. This sometimes restricts choice and specialized care. There is

usually a small copayment and often a referral from the primary care physician is necessary for specialists.

- Individual Plans: provided by an insurance company, with more restricted benefits than group plans.

Pre-Existing Condition Problem

If the diagnosis of Rett syndrome is made before the policy is in place, the insurance company has an option to reject the coverage if the policy has a "preexisting" clause. If Rett syndrome is not disclosed on the application for coverage, the insurance company can deny benefits when a claim is made, or may cancel the policy and refund the premium. Many insurance companies have clauses that limit the coverage for a condition which has been treated within three to six months of the start of the policy. Some companies exclude particular conditions for one year or even for the life of the policy. When the insurance company asks when the Rett syndrome first began, it is attempting to determine if the condition pre-existed the purchase of the policy. This can give the company space to deny the claim.

HMOs are prohibited from excluding pre-existing conditions, but they may limit the coverage offered. Most large group plans may go into effect after a specified time period of employment, and may not have limitations on pre-existing conditions.

The Americans with Disabilities Act of 1999 (ADA), prohibits employers from discriminating against people with disabilities. Under this act, employers are prohibited from discriminating against an employee from refusing to cover preexisting conditions.

Prenatal testing which determines that a child will be born with a genetic disorder causes the condition to be considered preexisting. This must be disclosed to health insurers. Therefore, if you are planning to have more children, it may be wise to obtain or change health insurance in advance.

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