



To The Parent of a Newborn with Down syndrome,
Congratulations! Welcome to the touching, inspirational and joyful world of raising a child with Down syndrome. The Down Syndrome Association Hudson Valley is an organization created by parents, for parents, who understand the mixed feelings you currently have. We wish to offer support and information to help you get started on your new, likely unexpected, journey. As parents who have walked in your shoes, we offer the suggestions and advice below.

- **Enjoy your baby.** Play, read, cuddle, talk, hug, kiss and gaze-figure out what your baby likes and do it often!
- **Connect with other parents of children with Down syndrome.** Look for a Parent Group in your area. Call or email the Down Syndrome Association Hudson Valley, 845-226-1630 or info@dsahv.org, to connect with other families. Parent Outreach Coordinators are available for phone calls and home visits to offer support and answer any questions you may have:

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- **Learn more about Down syndrome.** You probably have lots of questions about your child's diagnosis and what it means for the future. Much information is available on the internet; some through local bookstores and libraries. Check out the copyright dates. Anything published before 1990 probably is out-of-date and may not be very helpful. Woodbine House Publishing (www.woodbinehouse.com) is a wonderful resource on Down syndrome, including books on developing gross motor skills, fine motor skills, communication skills, teaching reading and math, and medical and surgical concerns. There are also helpful DVDs for children.
- **Find out about Early Intervention programs in your area.** Every state has an Early Intervention program for babies, from birth until the third birthday. This program is of no cost to families and provides valuable therapeutic services and education in the comfort of your own home. To contact your local county office, see the NY state website listed below.

Click on *Municipal/County Contacts for the Early Intervention Program* at the bottom of the page.

http://www.health.state.ny.us/community/infants_children/early_intervention/

- **Take care of yourself.** While it's probably the last thing on your "to do" list right now, you can better care for your child if you care for yourself, too. Spend time nurturing the relationships with your partner, other family members and friends. Accept help when it's offered.
- **Connect with a health care provider familiar with Down syndrome and its unique medical issues.** You may want to supplement care provided by your current doctor or nurse practitioner or you may be looking for a new provider. Some cities are lucky enough to have a Down Syndrome Clinic, specializing in the care of babies with Down syndrome. In other cities, you may want to look for a developmental pediatrician. Many HMOs and large clinic systems have a developmental pediatrician on staff. Providers who see lots of children with Down syndrome can be a wealth of information for you and your primary physician. Contact Down Syndrome Association Hudson Valley for physician recommendations, 845-226-1630.
- **Investigate county resources.** Check your local phonebook and look for a county department name such as Human Services, Community Services or Developmental Disabilities. Your county also may have a web site where you can find out how to connect with a case manager. A case manager should be able to help you find services that may benefit your child and your family. A case manager can help you connect with a school district, find available community services and tell you about financial resources you may qualify to receive. Families often use these services when their children are older. It's helpful to have connections in place to use when you need them.
- **Don't be afraid to grieve.** Grieving is normal and people express it differently - sadness, tears, anger, fear, depression or withdrawal. It's okay to cry. The baby you have may not be what you were expecting. Many parents of children with Down syndrome feel this way initially.