

# HELPING MYSELF Helping My Baby

## HELPING OTHERS AFTER DISCHARGE

### SUPPORT FOR ME

As the parent of a premature baby, you most likely have focused almost 100% of your attention and energy on this tiny new life. Understandably, your baby's health and continued growth and development will be a top priority. However, remember also to take care of your own physical and emotional needs. Doing so may help you to withstand the stress that you may face while caring for your baby in the neonatal intensive care unit (NICU) and at home.

There are many written resources, interactive websites, and support groups that can be a source of strength for you while you navigate the premature journey. Seek out advice, or share your story. Reaching out to others may help you to handle difficult situations, or just help you to cope.

**Share Your Story** is a March of Dimes® online community where you can connect with other families who understand your journey. Go to [www.shareyourstory.org](http://www.shareyourstory.org).

**Preemie Parenting** is a website with support group listings and testimonials. Visit [www.preemieparenting.com](http://www.preemieparenting.com).

**Preemie Care** is an organization for hospital and community-based parent support. It also offers a parenting education and resource listing by state. Go to [www.preemiecure.org](http://www.preemiecure.org).

**MOST** (Mothers of Supertwins) is a leading national provider of support and education for multiple-birth families. Visit [www.mostonline.org](http://www.mostonline.org) for more information.

**Prematurity.org** is a website with articles encouraging parents to advocate for themselves and for their children. Go to [www.prematurity.org/advocacy.html](http://www.prematurity.org/advocacy.html).

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### SUPPORT FOR MY BABY

Survival rates among premature infants have risen over the last 20 years. However, studies following these babies into school-age have shown that eventual learning and/or developmental disabilities and increased behavioral problems can occur.<sup>1</sup> Although your baby has progressed beyond the NICU, there is a chance that the road ahead may be difficult to navigate. It is possible that your child may have special needs now, or in the future. If so, this can be hard to accept. You may need to work hard to ensure that your child gets the best possible medical care. In most states, babies who have been in the NICU can be evaluated to find out if they have developmental delays or disabilities. Ask your healthcare provider about this evaluation. Know that there are many resources to help you find the right support as your baby develops, if you should need them.



<sup>1</sup>Source: Vanderveen, JA., et al. *Journal of Perinatology* (2009) 29, 343-351.



Helping Parents



Navigate The Premature Journey

Visit [www.specialdeliveryhandlewithcare.com](http://www.specialdeliveryhandlewithcare.com)

## RESOURCES THAT MAY HELP SUPPORT MY BABY

### Individuals with Disabilities Education Act — Part C, also known as Early Intervention (EI)

Early experiences have a big effect on a quickly developing brain. This suggests that early extra help for babies born prematurely may do a lot to improve their overall health. It may also improve how well they do in school and how they interact with other people. Our government recognizes this and, as a result, established Part C of the Individuals with Disabilities Education Act (IDEA), which is also known as Early Intervention (EI). Part C states that children in all 50 states under the age of three with developmental delays or a disability can receive EI services, such as speech, occupational, or physical therapies. It has been proven that these services, along with parent involvement, have a positive effect in the first three years of life. Because of this, your focus on your child's growth and development during the first 36 months is extremely important.

For more information about Part C programs in your state, go to: [www.nectac.org/contact/contacturl.asp?gc=101](http://www.nectac.org/contact/contacturl.asp?gc=101).

There are many national organizations with state and local chapters that support infants and toddlers with special needs and their families. These groups work directly with families to make sure that there are appropriate services available for their children.

Following is a list of some of these resources:

**EIFA (Early Intervention Family Alliance)** is dedicated at community, state, and national levels to improving the lives of infants and toddlers with disabilities. They partner with families and focus on Part C policies. Visit [www.eifamilyalliance.org](http://www.eifamilyalliance.org).

**IDEA Infant and Toddler Coordinators Association** supports Part C coordinators and develops recommended models and programs of quality services for infants and toddlers who need them. Visit [www.ideainfanttoddler.org](http://www.ideainfanttoddler.org) to sign up for an e-newsletter, or see how IDEA can connect you with resources to help meet your child's needs.

**PAT (Parents As Teachers)** is a group of parent educators who support parents with information about each stage of their child's development. To find one of about 3,000 locations that offer PAT services, visit [www.parentsasteachers.org/site/pp.asp?c=ekIRLcMZJxE&b=1595095](http://www.parentsasteachers.org/site/pp.asp?c=ekIRLcMZJxE&b=1595095), or call 866-728-4968.

**AAHBEI (American Association for Home-Based Early Interventionists)** values the home as an environment for EI and gives services and support to children with special needs. It also offers newsletters and networking support for families. Call 800-396-6144.

## SUPPORT FOR OTHERS

Once you are comfortable taking care of yourself, as well as your baby, you may feel a desire to help others who will travel down the path of prematurity. You might choose to have a public voice and to urge lawmakers to focus on the health and treatment of premature babies. Or, you may decide to stay involved in the same local support groups that have provided comfort for you and your family. In whatever way you choose to be active, your support can improve the lives of premature babies.

The "Preemie Act" that was signed into law in late 2006 is a great example of how public voices can affect legislation in our country. Supported by the March of Dimes® and other advocacy groups, this bill expands research on premature births, improves education for all expectant mothers, and provides better treatment for babies born early. If you are interested, you may want to educate yourself on key public priorities and legislative issues, such as the ones that initiated the "Preemie Act." Visit the March of Dimes® advocacy web page at [www.marchofdimes.com/aboutus/855.asp](http://www.marchofdimes.com/aboutus/855.asp).

There, you can learn about current events surrounding prematurity and find ways to help change public policy. There are explanations about current legislation under consideration, with links to e-mail addresses for U.S. Senators to whom you can voice your support. Another informational resource is the American Academy of Pediatrics (AAP). On the AAP website, you can follow links to summaries of current legislative issues and learn about how the AAP Division of State Government Affairs helps state AAP chapters as they advocate for children's health. Visit [www.aap.org/advocacy.html](http://www.aap.org/advocacy.html) for more information.

**This information is for educational purposes only and is not intended to substitute for professional medical advice. Always consult with a healthcare professional if you have any questions about your health, or the health of your child. The third-party websites we reference are not under the control of MedImmune, and access to these websites is at your own risk. MedImmune is not responsible for their accuracy or reliability, and the inclusion of these websites does not constitute an endorsement or approval of any of the contents.**



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