

# Nursing and Down Syndrome:

A short guide to breastfeeding your baby







**Congratulations!** By following the advice in this brochure, you are taking an important first step toward successfully breastfeeding your baby with Down syndrome (DS). As with everything in life, being prepared is essential and we want to help you have the best chance for a happy, healthy breastfeeding relationship.

Most babies with DS can breastfeed just like any other baby. There may be bumps in the road that can complicate breastfeeding or delay its onset, but in most instances breastfeeding is possible. This brochure is designed to help you understand and prepare for some of the challenges you and your baby may face.

# **Benefits of Breastfeeding Your Baby** with Down Syndrome

- Breast milk provides an ideal source of nutrition, is easily digested, and is well tolerated by babies.
- The physical act of nursing is a type of speech therapy, helping to shape the upper palate, and laying the groundwork for future speech.
- Your baby may be born prematurely, with a less mature immune system. The antibodies in your breast milk provide some protection against illness.
- Breastfeeding can encourage the important bond between you and your baby.
- Breastfed babies have a decreased risk of ear infections, severe lower respiratory infections, colds, allergies, asthma, and celiac disease.

## **While You Are Pregnant**

Tell your medical team about your intention to breastfeed and request that a note be placed in your chart so that all of your providers are aware of your wishes. Additionally, you can:

- Take a breastfeeding class to help prepare you for any challenges you may have.
- Contact the lactation consultants at the hospital where you are delivering to let them know that you want to breastfeed and that you may require extra assistance.

- Call your health insurance provider to check if your policy covers a breast pump. If you are separated from your baby after birth, you may need a hospital-grade breast pump to establish your milk supply or to express breast milk long term.
- Ask your local DS organization to connect you with lactation professionals who have worked with babies with DS and with moms who may be willing to support you in this process.
- Direct your medical professionals to www.juliasway.org so they can better understand how to help babies with DS breastfeed successfully.

#### **First Hours**

After your baby is born, there are several things you can do to get breastfeeding off to the best start. Most importantly, make sure everyone on the team is aware of your desire to breastfeed. In addition:

- Put your baby to breast as soon after birth as possible, preferably within the first hour.
- Practice skin-to-skin contact as much as possible. In addition to helping you establish a milk supply, skin-to-skin contact has several other benefits to both you and your baby.
- If your medical team wants to keep a close eye on intake, request pre- and post-breastfeeding weights to assess how much milk your baby is taking at each feeding. *(continued)*

#### **If Your Baby Has Difficulties Breastfeeding**

Remember that babies with DS do not seem to have a "window" in which they must learn to breastfeed. As long as you protect your milk supply by expressing your milk, you have a good chance of being able to transition your baby to the breast.

- If your baby can't breastfeed soon after birth, you need to start expressing your milk, ideally within 1-3 hours of delivery. This will help you establish your milk supply and will stimulate ongoing milk production.
- Request assistance from the hospital's lactation consultants right away. They may use a variety of different devices that can help make breastfeeding more effective. Ensure that you know how to use these before you leave the hospital.
- Request a consultation with a speech pathologist or feeding team. They can collaborate with your lactation consultant to help your baby transition to oral feedings.



#### **COMMON CHALLENGES**

These challenges may seem overwhelming at first but most can be overcome with time and support.

- Prematurity
- Heart or other medical conditions
- Low muscle tone
- Poor endurance
- Weak suck
- Excessive sleepiness

#### If You Need to Pump

Julia's Way surveyed mothers of babies with DS and discovered that up to 70% had to pump at some point during their baby's breastfeeding journey. Pumping can be tiring, and it may be challenging to establish your milk supply if your baby cannot nurse directly, but it can be done!

#### **Get the Most out of Your Pumping Sessions**

- Hand expression can be more effective at milk removal in the first 24-48 hours. Your lactation consultant can instruct you on how to do this. Milk that is expressed by hand has also been shown to have higher fat content.
- Pump at least 8 times every 24 hours to establish an adequate milk supply. This will ensure that you will have the opportunity to transition your baby to breast in the future.
- When establishing your milk supply, more frequent pumping is more beneficial than longer pumping sessions.
- Massaging your breast for a few minutes before you start pumping can encourage let down and help maximize your milk supply.
- Listening to relaxing music while pumping, especially while looking at photos of your baby, has been shown to have a positive effect on the quantity and fat content of milk.
- Try the "milk shake"! Lean forward and let your breasts hang down and gently shake them back and forth. This is thought to help release the milk droplets from the walls of the ducts.
- Consider purchasing two pumping kits to cut down on washing parts as frequently.
- Make sure to read the guidelines from the Center for Disease Control for keeping your pumping parts clean and for tips on how to store your milk.

## **Going Home**

You may find it easier to concentrate on your breastfeeding relationship once you are in a familiar environment.

- To ensure your baby is eating enough, track your baby's feeding and wet/soiled diapers in a paper journal or through a smart phone app.
- Consider renting a digital scale to do pre- and post-breast-feeding weights at home to ensure that your baby is transferring enough milk.
- Find a comfortable chair and a good pillow to support you and your baby. Good positioning will help your baby latch better and allows for optimal milk transfer.
- Contact your local early intervention (EI) program when your baby is born and arrange to have a developmental assessment as soon after discharge as possible. This team will assist your baby in developing to his or her full potential and can provide you with ideas for positioning, play, and feeding.

For more information, support, and resources, visit our website at www.juliasway.org or email love@juliasway.org.

MEDICAL PROFESSIONALS: Request FREE copies of this brochure at www.juliasway.org.