

- \* Anencephaly Support - Stories of families who chose to continue a pregnancy with an anencephaly diagnosis. [www.anencephalie-info.org](http://www.anencephalie-info.org)
- \* Heart Defects - [www.littlehearts.net](http://www.littlehearts.net)  
[www.congenitalheartdefects.com](http://www.congenitalheartdefects.com)  
[www.cherubs-cdh.org](http://www.cherubs-cdh.org)
- \* Genetic Conditions/Rare Conditions - Support groups and info on specific diseases.  
[www.kumc.edu/gec/support](http://www.kumc.edu/gec/support)
- \* Problematic Multiple Pregnancy:  
Mothers of SuperTwins: Support and resources for families with triplets, quads, etc  
[www.mostonline.org](http://www.mostonline.org) [www.twin2twin.org](http://www.twin2twin.org)
- \* Sisters of Life: This group of sisters is consecrated for the protection and enhancement of the sacredness of human life. Get spiritual support for your journey with your little one. (718)881-8008 or (212)397-1397.
- \* A Place To Remember: Uplifting support materials for anyone touched by a crisis pregnancy or the death of a baby.  
[www.aplacetoremember.com](http://www.aplacetoremember.com)
- \* A Very Special Baby Book - by Rhonda DeBough. A beautifully illustrated baby book made for babies born with special needs. <http://www.home.earthlink.net/~rhondadebough/index.html>

Helpful Literature: Letters to Gabriel by Karen Garver Santorum: A story of a family's journey with their son who had a fatal kidney condition.

Choosing Naia: A Family's Journey by Mitchell Zuckoff - A Down's Syndrome Story

You Are Not  
Alone.....



These little  
ones leave  
footprints on  
our hearts.....

*Parents never expect to get the devastating news that their baby will have a serious medical condition. Hopes and dreams are shattered.*

*This brochure will connect you with resources and support so you can carry your baby to term. You can hold and love your baby. You can make memories that will last a lifetime. You are not alone.*



**Carrying  
to Term  
When  
Your  
Baby has  
a  
Serious  
Diagnosis**



**Resources  
and Support**

## You want to carry your baby to term in spite of the diagnosis. ....But how?

Modern technology and prenatal testing have made it possible to know more about babies before they are born than ever before.

When results of these tests are abnormal, parents are faced with a difficult decision. They may be presented with a decision no parent should ever have to make--carrying a child with a serious diagnosis to term or terminating the pregnancy.

Parents, like you, who decide to continue their pregnancies are not alone. This guide will provide you with information, resources and support to help you get through this most difficult time.



### Websites and Resources:

- \* **Be Not Afraid Website:** A website devoted to the stories of families that have carried their babies to term in spite of an adverse prenatal diagnosis. This site includes both fatal and nonfatal defects. [www.benotafraid.net](http://www.benotafraid.net)
- \* **Carrying To Term Pages:** A site with many practical tips and support for families who choose to carry to term. Written by a mom who has "been there". A great site for sample birth plans. [www.geocities.com/tabris02/](http://www.geocities.com/tabris02/)
- \* **Waiting with Love:** For parents who choose to continue a pregnancy knowing their baby has a potentially fatal condition. [www.erichad.com/wwl](http://www.erichad.com/wwl)
- \* **Morning Light Ministry Website and Hope in Turmoil Booklet:** A faith based website with great resources to help you. The Hope in Turmoil Booklet is a "must have".  
<https://ca.geocities.com/morninglightministry@rogers.com/hopeinturmoil.html>
- \* **Baby Center Bulletin Boards:**  
Continuing a Pregnancy with a Poor Prenatal Diagnosis:  
[www.babycenter.com/bbs/1311592](http://www.babycenter.com/bbs/1311592)

### If Your baby is diagnosed with a fatal or potentially fatal condition:

- \* **Perinatal Hospice Support**  
Perinatal Hospice Services are offered through Hospice Care Network.  
Contact: Mary Gravina, LCSW  
Director of Perinatal Hospice Program  
631-666-6873 extension 203.  
[www.hospicecarenetwork.org/support.html](http://www.hospicecarenetwork.org/support.html)

### You can contact these moms who carried to term through email on the following websites:

- \* **Grace Anne Nugent Website:** A story of a family's journey with their daughter Grace who had a potentially fatal condition. Great resource page.  
[www.graceannenugent.netfirms.com](http://www.graceannenugent.netfirms.com)
- \* **Jonathan Dobkowski Website:**  
The story of a family's journey with their son Jonathan who had a fatal condition. [www.angelfire.com/ny5/jonathandobkowski](http://www.angelfire.com/ny5/jonathandobkowski)

### Support for Specific Disorders:

- \* **Down's Syndrome Support:**  
Based on Down Syndrome listserv with lots of good links.  
[www.nas.com/downsyn](http://www.nas.com/downsyn) and  
[www.acds.org](http://www.acds.org)
- \* **Spina Bifida Support:** Spina Bifida Association of America  
[www.sbaa.org](http://www.sbaa.org)  
[www.waisman.wisc.edu/~rowley/sb-kids/](http://www.waisman.wisc.edu/~rowley/sb-kids/)
- \* **Trisomy 18 Support:** An online support for families faced with a trisomy 18 diagnosis. It has a bulletin board where you can connect to other moms who have carried their babies to term too.  
[www.trisomy18support.org](http://www.trisomy18support.org)
- \* **Potter's Syndrome/Renal Agenesis:** Lots of support including birth plans. [www.pottersyndrome.org](http://www.pottersyndrome.org)