Thank you for supporting our work

We need your support in order to be effective and also to raise funds for vitally important research projects that can improve the lives of all children and adults who have Down’s syndrome.

BRIGHT BEGINNINGS will lead to a BRIGHTER TOMORROW
When we all work together to help our children.

About the DSRF-UK  1996-2011

The Down’s Syndrome Research Foundation is a registered charity in the UK established in 1996 by parents who wanted a greater emphasis on medical research and healthcare issues. Fifteen years on, we are a National Charity with members throughout the UK and supporters around the World. Our work touches the lives of thousands of families where there is a family member has Trisomy 21.

What is Trisomy 21?

In 1959, a French geneticist, Professor Jerome Lejeune, discovered that Down’s syndrome was caused by the presence of an extra copy of chromosome 21, making 47 chromosomes in all instead of the usual 46 chromosomes. This results in about 60,225 genes in every cell of the body and the brain instead of the usual 60,000 genes. A difference of less than 0.4%. This tiny difference is enough to cause changes to the biochemistry that results in some health and development problems including memory problems that need research and treatment. The health and development issues are called Down’s syndrome, named after a doctor who first wrote them down. But he was just making some observations that later became named after him. Trisomy 21 is the correct medical name for this condition. Every child is different, but many aspects of the syndrome are similar and treated very successfully. Research is underway to find treatments for every problem including the problem with impaired memory. Huge advances have already happened because parents took the lead. Especially with new education methods. But no child wants to be special they just want to be ordinary and part of the human family. Parents are surrounded by people who underestimate what our children can achieve. They often have to fight for access to services they need. This results in parents who are afraid to dream. But this booklet is proof that these are amazing children who are tough, long suffering and tolerant and a great human resource. They know who you are and they want your love and approval always.

Facts

– About 700 babies are born with Trisomy 21 in the UK each year.
– For every 1000 births – one baby will have Trisomy 21.
– An estimated 60,000 people in the UK have Trisomy 21.
– Trisomy 21 is the cause of Down’s syndrome.
– Down’s syndrome affects people of every race and standing.
– Research is underway to treat every aspect of this syndrome.

ACKNOWLEDGEMENT

BRIGHT BEGINNINGS is reprinted in the United Kingdom with the kind permission of the Down Syndrome Association of Middle Tennessee. We want to thank everyone involved in the original design of this attractive and well designed booklet. This is an outstanding achievement that finds its best reward as these booklets are seen and read by more and more parents in the USA and now in the UK. We acknowledge all copyrights as stated throughout this booklet, and we reprint with their permissions. This is the 4th edition, additional information relative to the UK and Ireland has been added. Healthcare concerns and parental concerns in the UK are the same as they are in the USA.

Dr. Liz Elliott  DSRF-UK Chairman

Disclaimer

The Down’s Syndrome Research Foundation funds research and provides information on issues connected with Down’s syndrome. If you are concerned about the well-being of a child or an adult with Down’s syndrome in your care, you should consult a Doctor.

In cases of medical emergency you should seek immediate medical assistance and call an Ambulance.

© Copyright 2005, 2006, 2011
The Down’s Syndrome Research Foundation Limited.
The Saunderton Estate, Bucks, HP14 4BF
Company 3228419 - Registered Charity 1058548
Email: dsrf@dsrf-uk.org
Congratulations! You have just become the parent of a remarkable little person, a baby who loves you and needs you! It’s true that in addition to the many needs all newborns have, this little one has special needs that may seem a bit overwhelming to you right now. Despite this, he or she is first and foremost a baby – your baby.

Your baby has an extra chromosome, this is a normal chromosome and the condition is called ‘Trisomy 21’. Doctors will say the baby has Down’s syndrome but “Down” is just the name of the doctor who first noticed these children were different and this was over 100 years ago. Today we have very advanced medical resources and doctors have the skills to take good care of you and your baby. You can expect your baby to become an important member of your family in every way … in temperament, in looks, in sense of humor, and talent. You have every right to celebrate the miracle of his or her birth! This newborn packet has been compiled for you by parents who have been where you are today.

We are all parents of children who have Trisomy 21 and we love our children! We are proud to be their parents and can’t imagine life without them. We are excited for you as you begin this uncommon journey with your child. Together you will learn, you will grow, you will cry, and you will rejoice as you experience this adventure called Trisomy 21 (or Down syndrome). Please keep in mind that these are just names for something your child has, it is not something he or she is.

Your child is a human being, a family member and an individual with feelings, needs, wants, numerous capabilities, and great potential. With this child will come the opportunity to teach your family and friends about Trisomy 21, they will have questions. To help you become informed we have included information that we, as parents of children with Down’s syndrome, have found helpful. We urge you to research information further if you wish; this booklet is just to get you started in the right direction. Again, congratulations and good luck to you. We welcome you and your new baby into our DSRF-UK family!

DSRF-UK

The Down’s Syndrome Research Foundation Ltd.
website: www.dsrfr-uk.org

The speed that we can make progress – depends on your support - join now
send us an email - with your name and address - become a member of the DSRF-UK

membership@dsrfr-uk.org
When doctors suspect that a baby may have Down's Syndrome, a blood sample is taken to allow a chromosomal analysis to be done. Normally there would be 46 chromosomes in each cell (23 from the father, 23 from the mother).

If the baby has an extra copy of chromosome 21 this is called 'Trisomy 21'. Children with Trisomy 21 are said to have Down's syndrome.

In fact they have a genetic disposition to develop various aspects of Down's syndrome. There is no fixed pathology and no certainty of outcome. Every child is different. Parental genes and the environment will play a major role in every child’s development. Each child is different and unique.

A syndrome is a group of concurrent medical observations. In 1866 Dr John Langdon Down documented a syndrome among some children in his care. He was credited with the discovery so it was called “Down's syndrome”.

“Down”, is just the man's name. It has no negative meaning at all. Our children are decidedly positive, and definitely UP-beat kids.

In 1959 Professor Jerome Lejeune, a French geneticist, who dedicated his life to helping our children, discovered a third set of genes at chromosome 21 and this was identified as the underlying cause of the health and development problems seen in Down's syndrome. This discovery was called Trisomy 21.

In approximately 95% of people with Down's syndrome, there is an extra 21st chromosome in each cell. Trisomy 21 is the correct medical name for this fixed condition.

Two to three percent of people with Down's syndrome have a chromosomal abnormality known as translocation. In translocation, an extra part of the 21st chromosome is attached or translocated to another chromosome. A translocation may indicate one of the parents is carrying chromosomal material that is arranged in an unusual manner. If the Down’s syndrome has been inherited this way, the chance of future children having Down's syndrome may increase significantly. It is recommended that parents of children with translocation have their own chromosomes analyzed.

Another chromosomal abnormality, mosaicism, is found in approximately two percent of people with Down's syndrome. Instead of having an extra 21st chromosome in every cell, people with mosaicism have 46 chromosomes in some cells and 47 in others. It is the result of an error in cell division soon after conception. In this case only some of the problems are seen, and it can be hard to detect a child who has a mosaic of trisomy 21 cells.

Trisomy 21 is a genetic accident that can happen to any parents. There is nothing the mother could have done during the pregnancy to cause the baby to have Trisomy 21 or Down's syndrome.
Why does the doctor suspect my baby has Down’s syndrome?

There are several characteristics that are typical of babies with Down’s syndrome. They include:

- low muscle tone
- eyes that appear to slant upward
- a flat nasal bridge
- relatively small nose and ears
- a single horizontal crease (simian crease) across the palm of the hand
- small skin folds (epicanthic folds) in the inner corner of the eyes
- more space between the large and second toes
- a large tongue in relation to the size of the mouth

Will my baby be healthy?

Children with Down’s syndrome may face health complications beyond the usual childhood illnesses. Problems such as some congenital malformations of the heart can be life threatening. Others are of much less significance.

More than 40 percent of children born with Down’s syndrome have a congenital malformation of the heart, a percentage that suggests every baby with Down’s syndrome should have an echocardiogram and be examined by a pediatric cardiologist. The diagnosis of a heart problem does not necessarily mean the baby is, or will become, seriously ill. The significance of heart problems varies greatly.

It is important that all infants with Down’s syndrome have hearing and vision evaluations between six and 12 months of age – earlier if problems are evident. A high percentage of children with Down’s syndrome experience some degree of hearing loss, most often due to frequent ear infections. Adequate hearing is critical to the development of good language skills, so periodic medical check-ups should include visualization of the ear canals to ensure no infection is present. This may require a visit to an ear specialist. Many children with Down’s syndrome also have vision problems. An ophthalmological exam is recommended during the baby’s first year.

Where do I go from here?

The prospect of caring for a baby with Down’s syndrome can be overwhelming. The job of parenting may seem suddenly complicated and unfamiliar. Many parents doubt their ability to raise a child with special needs. It is important to remember that there are many resources available to you. Most communities offer a range of early intervention programs designed specifically to enhance the progress of children with special needs. Early intervention programs include a wide variety of services provided by specialists in early childhood development. Among the services most often required by children with Down’s syndrome are speech, physical, and occupational therapies.

In addition, children with Down’s syndrome benefit from many of the same community programs and services other children do, such as play groups, nursery school classes, swimming and music lessons, story times at the library, and other social activities.

Aside from the expertise of professionals, parents can find information and support from parent groups that meet regularly throughout the country. Numerous publications about Down’s syndrome, including books, periodic journals, magazines, and newsletters provide parents with guidance as well as up-to-date information.

**DSRF Note: Parent Support Resources around the UK are listed on Page 34. These organisations will have services in your area and you should make use of those free services. Information in books and in libraries is often very old and out of date. Bright Beginnings has some of the most up-to-date information available anywhere. Parents become experts as they stay up-to-date on medical progress and new ideas on Down’s syndrome and as they network with other parents.**

**You can contact the DSRF for the latest information and advice. Email: dsrf@dsrf.co.uk – or visit our website www dsrf.co.uk**

Special thanks to the National Association for Down Syndrome (NADS), P.O. Box 4542, Oak Brook, Illinois 60522-4542, Phone (630) 325-9112, for permission to reprint this helpful information. Medical resource: Nancy Rozien, M.D., Director, Down Syndrome Clinic, University of Chicago Hospitals.
to have a baby with Down’s syndrome.

Though the incidence of having a baby with Down’s syndrome increases significantly with age, statistics indicate the majority of children with Down’s syndrome are born to women younger than 35. The average maternal age is 28 years.

In the past it was incorrectly assumed that all people with Down’s syndrome had severe mental impairments. Current research indicates that the majority of people with Down’s syndrome have mild to moderate impairments.

When a baby is born with Down’s syndrome, quite frequently Intelligence Quotient (IQ) becomes the main focal point. Many people attempt to predict an infant’s IQ or potential, and yet we know it is impossible to determine any infant’s IQ.

As with all children, youngsters with Down’s syndrome acquire new skills and develop as individuals as they grow, albeit at a slower pace than children without Down’s syndrome. There are individual differences in the development of all children. It is impossible to predict the future strengths and weaknesses of ANY baby.

In general, the current achievement norm for teenagers and adults with Down’s syndrome is probably not a good indicator of what will be typical in the future. The common attitude toward all people with disabilities is more and more one of acceptance. Education, job and housing opportunities have increased significantly during the past years and, it appears, will continue to do so.

As parents attempt to imagine their child’s future, it is helpful to realize that there is no standard profile of a person with Down’s syndrome. As is true for everyone, the skills and knowledge he or she acquires will depend on life experiences as well as innate abilities.
Breastfeeding the Baby with Down’s syndrome

The best advice your pediatrician can give you is to take your new baby home and shower him with all the love, warmth, security and personal attention that the family can provide. This will help your baby develop to his fullest potential. The majority of babies with Down’s syndrome are happy, playful, and a delight to the whole family. Your baby will learn more quickly in a happy and stress free environment and breastfeeding provides that environment. Encouragement and smiles for your baby will be returned as smiles and encouragement from your baby.

Please be aware that other mothers have gone through the emotions that you are feeling right now. You are not alone. These parents will be happy to share their experiences and the information they have gathered that will help you nurse your new baby successfully.

Can a baby with Down’s syndrome learn how to nurse and be strong enough to nurse successfully? The answer is YES! Sometimes it takes a little longer for the baby to learn how to suck well. It might take longer for even an experienced nursing mother to learn the particular “trick” to help your new baby with Down’s syndrome nurse successfully.

Breastfeeding not only strengthens the maternal-infant bond, but it is also a major contributor to the baby’s nutritional well-being. The advantages of breastfeeding take on added significance for the baby with Down’s syndrome. They have a greater susceptibility to infection than other infants so the immune factors present in colostrum and breast milk are especially valuable. Recent research shows that breast milk contains lactoferrin and transferrin, which prevent the growth of harmful bacteria in the intestinal tract. The bifidus factor (contained in breast milk) also promotes the growth of friendly bacteria in the intestinal tract. Further protective action is gained from lysozyme found in breast milk that attack and break down bacteria. Antiviral factors, such as interferon, are also present in human milk. These are just a few examples of why breast milk is the best food for the baby. Of special interest is the high level of trauine (an animo acid) and lactose found in breast milk. These two nutrients have been found to be essential for growth in early infancy and especially for brain development.

Many pediatricians tell their new mothers that nursing is the very best thing for new infants with Down’s syndrome. It is the perfect food for their immature digestive systems and it provides good tongue thrust and jaw development.

When the baby is born with Down’s syndrome, there are varying degrees of concerns. The baby may be a little sleepier and have a poor sucking reflex, while others may have respiratory problems and more serious difficulties. If your baby is weak at birth, he may experience some difficulty in learning to suck and swallow, so you will need to be calm and patient while he learns.

Babies with Down’s syndrome are often more prone to respiratory infections and digestive upsets. Breastfeeding lessens the incidence of both of these problems and probably reduces the severity of them if they should occur. Babies with Down’s syndrome are often placid and sometimes have poor muscle tone and generalized weakness at birth. Therefore, the mother will have to learn to be a clock watcher, picking the baby up frequently and offering the breast, rather than waiting for him to cry to be fed. The baby should be encouraged to nurse about every two hours during the day and several times during the night.

Sometimes mothers have trouble getting the baby’s tongue down from the roof of his mouth. To help with this concern, insert the tip of the mother’s little finger between the roof of the baby’s mouth and the tongue in an upside-down position, then turn the finger over. To condition the sucking reflex, the procedure could be repeated four or five times before each nursing starting with the finger at the front of the baby’s mouth and pushing it slowly into the baby’s mouth so the baby will think he is drawing in.

When you get home from the hospital it is important to remember to take care of yourself. You need to rest and to watch your nutrition, just as you did when you were pregnant. To assure yourself of these things, a mother’s helper is a wonderful asset – someone to care for you, while you care for your baby.

Of course you will be in close contact with your doctor who will continue to evaluate your baby’s progress. Because some babies with Down’s syndrome don’t gain as well as they should, doctors sometime suggest solids earlier than usual. Let your doctor’s advice and the baby’s needs be your guide. Many babies with Down’s syndrome are slow, leisurely nursers, so long feedings are to be anticipated. You’ll both thrive on these quiet times; this can be a cozy, relaxing time.

The rewards of nursing your baby are well worth the extra effort, so don’t be discouraged if you encounter problems. With your loving help, the baby will catch on. A good knowledge of breastfeeding is helpful. The Womanly Art of Breastfeeding can be obtained from the local La Leche League and offers excellent information, and encouragement. Lactation specialists are also available through most hospitals and WIC (Women, Infants and Children) programs, to offer encouragement and support and to help you and your new baby learn together the art of breast-feeding.

New parents often don’t realize that children with Down’s syndrome can have nearly normal social and emotional development. Babies with Down’s syndrome thrive on the stimulation, the attention, and the tender, loving care that all children need. They return love one-hundred fold. ☺

NOTE: Parents in the UK have access to a Health Visitor who has experience in supporting mothers with breast feeding difficulties. You should ask your Health Visitor if you need help.
Foods to Watch

Some foods require caution for any child who is still learning to handle food in their mouth. Children with Down’s syndrome often need to be cautious with these foods until age 5 or beyond. If your child has not yet mastered a “mature rotary chew,” only offer these foods with strict, attentive supervision (or not at all).

**Hard, Small Foods:**
- Nuts
- Seeds
- Popcorn
- Raisins
- Hard Candies
- Raw Carrot Sticks
- Chips
- Snack Puffs

**Slippery Foods:**
- Whole Grapes
- Hot Dogs
- Sausage
- Olives
- Large Piece of Meat

### Parent Perspective

“My daughter never did learn to latch on and nurse; her heart condition made her so sleepy all of the time. I wanted her to have a breast-milk diet to help compensate for all of her health problems, such as an already-compromised immune system, so I borrowed a hospital-grade breast pump from the WIC program. I ended up pumping for 8 months, and I know this helped her stay healthy.”
Congenital Heart Disease

Congenital heart disease means one or more heart defects are present at the time of your baby's birth. It is one of the most common birth defects, affecting about 1 in 100 babies, and 30–50 percent of babies who have Down's syndrome. Congenital heart disease causes shortness of breath; this may affect their feeding, growth and activity. The most common type of congenital heart defect is a septal defect or hole in the inner wall (septum) between either the upper two chambers (atrial septal defect or ASD) or the lower two chambers (ventricular septal defect or VSD) of the heart. With either defect, some oxygenated blood passes from the left side of the heart and is sent back into the lungs instead of circulating throughout the body. Both defects are common in the hearts of children with Down's syndrome. Only about 1 in 3 affected children requires heart surgery, and emergency surgeries are rarely necessary to save a young baby's life. If doctors suspect your child has a congenital heart defect (from hearing a heart murmur, for example) he or she will arrange for a cardiologist to perform an ECG to monitor the electrical activity of the heart and an echocardiogram or ultrasound to see how big the hole is. The cardiologist will make recommendations to a heart surgeon, who will perform any needed surgery. This is a frightening aspect to parents having their small, helpless baby subjected to such major surgery; doctors, however, successfully perform these routine surgeries daily. They are happy to answer any questions you might have.

Parent Perspectives

“Nothing had ever caused me greater stress than contemplating our daughter’s open-heart surgery. I assumed it would take months for her to recover. Was I surprised to have her out of the hospital within 5 days! It was amazing how quickly she recovered, and how much more energy she had post-operatively. She went from having four or five naps a day to having first two and then one.”

“I was shocked at how many tubes our son had when he came out of surgery, and how pale he was. But there was remarkable improvement in his appearance with each hour that passed. Kids are so resilient. This surgery was tough emotionally on us as his parents, but he probably doesn’t even remember any of it. He still has the scar, but he also has a mended broken heart!”

For more information:

See Your Doctor.

Parent Support Down’s Heart Group P.O. Box 4260 Dunstable LU6 2ZT Phone: 0845 166 8061 email: info@dhg.org.uk website: www.dhg.org.uk
What is Early Intervention, and what is its purpose?
The concept of “early intervention” is quite simple. If a child with a developmental delay receives proper help early on, problems in the future may be minimised. A child, his/her family, and the educational system will benefit by the reduced need for long-term intervention throughout the child’s school years.

What kinds of things will my child do in Early Intervention?
Your child will participate in a variety of activities planned by therapists, teachers, and nurses. The setting for these activities – which are designed to provide physical, occupational, and speech therapies as needed – may include regularly scheduled home visits, play group activities, individual therapy at home, day-care or hospitals, or other combinations that work for your family.

Will I have any say regarding my child’s participation in any of these therapies?
Absolutely, after eligibility is determined. Children with Down’s syndrome usually qualify.

PT, OT, & Speech Therapy

Physical Therapy (PT) is the treatment of children with physical disabilities by a professional physical therapist who is educated and trained in the diagnosis and treatment of children with physical disabilities. The goal of PT is to improve care and provide a treatment programme to obtain or restore the highest level of independence and function in quality of movement, walking, strength and endurance, gross motor skills, posture, positioning for functional skills, coordination, and mobility for the child with the disability.

Paediatric Occupational Therapy (OT) is the treatment of children with physical, emotional, and/or intellectual disabilities ages birth to 21 by an occupational therapist educated in a variety of diagnoses and therapies for such children. The goal of OT is to help make learning possible by helping children develop the underlying skills that will lead to independence in personal, social, academic, and vocational activities. This includes remediation for difficulties the child may encounter with ADLs (Activities of Daily Living) such as dressing, grooming, feeding, etc.

Pediatric Speech Therapy addresses the child’s complete communicative needs. This often begins with the development of non verbal communicative skills such as attending to the speaker and the activity, taking turns, and making appropriate eye contact. It is designed to help with speech disorders, often referred to as articulation or phonological disorders – problems with the way sounds are made or how sounds are sequenced to form words; oral-motor problems resulting in difficulty producing speech sounds; and delays in feeding skills. A speech-language pathologist is a specialist in the normal development of human communication.
Development Benchmarks

### Different Accomplishments at Different Ages

<table>
<thead>
<tr>
<th></th>
<th>Down syndrome Age range</th>
<th>Typical Age range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GROSS MOTOR</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sits alone</td>
<td>6-30 months</td>
<td>5-9 months</td>
</tr>
<tr>
<td>Crawls</td>
<td>8-22 months</td>
<td>6-12 months</td>
</tr>
<tr>
<td>Stands</td>
<td>1-3½ years</td>
<td>8-17 months</td>
</tr>
<tr>
<td>Walks alone</td>
<td>1-4 years</td>
<td>9-18 months</td>
</tr>
<tr>
<td><strong>LANGUAGE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First word</td>
<td>1-4 years</td>
<td>8-23 months</td>
</tr>
<tr>
<td>Two word phrases</td>
<td>2-7½ years</td>
<td>15-32 months</td>
</tr>
<tr>
<td><strong>PERSONAL/SOCIAL</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responsive smile</td>
<td>1½-5 months</td>
<td>1-3 months</td>
</tr>
<tr>
<td>Finger-feeds</td>
<td>10-24 months</td>
<td>7-14 months</td>
</tr>
<tr>
<td>Drinking from cup (unassisted)</td>
<td>12-32 months</td>
<td>9-17 months</td>
</tr>
<tr>
<td>Uses spoon</td>
<td>13-39 months</td>
<td>12-20 months</td>
</tr>
<tr>
<td>Bowel control</td>
<td>2-7 years</td>
<td>16-42 months</td>
</tr>
<tr>
<td>Dresses self (unassisted)</td>
<td>3½ - 8½ years</td>
<td>3½-5 years</td>
</tr>
</tbody>
</table>

Source: National Down Syndrome Society, USA

Folic Deficiency  See DVD 2

Jill James was speaking on this important subject at our conference in 2006. See page 36 to obtain this DVD

From USA Today (9-29-99): Taking folic supplements, already shown to cut the chance of having a baby with spina bifida or related birth defects, also might reduce the chance of Down syndrome, according to lead author S. Jill James, whose research appears in the October 1999 issue of the American Journal of Clinical Nutrition. Food and Drug Administration researchers compared blood samples from 57 mothers of children with Down syndrome and 50 mothers of children without Down syndrome. The average age of both groups was 30. Mothers of children with Down syndrome appeared to be more likely to have problems metabolizing folate, another name for folic acid, than other mothers. The former group tended to have higher levels of the amino acid homocysteine, a sign of low levels of folic acid. They were also more likely to carry a common alteration in a gene for an enzyme needed for folate metabolism. Women with the alteration were 2½ times more likely to have an affected child. While this is the first report of a possible nutritional link to Down syndrome, James says, “Clearly, it’s not the cause, or we’d have a lot more babies [with Down’s syndrome.]” More research is still needed to determine the vitamin’s impact on Down syndrome.

Additional information:
THE “RED BOOK”

Your NHS Healthcare Provider will give you a “Red Book”. This is an important record of your child’s Immunisations, growth and development. Make sure you have Down’s syndrome growth charts and related information. This book contains other helpful information you may need.

UK & Ireland Suggested Schedule of Health Checks
Based upon information published by Down’s Syndrome Medical Interest Group (DSMIG) UK and Ireland.
DSMIG - UK: www.dsmig.org.uk - DSMIG - Ireland: www.downsyndrome.ie
Refer to these websites for up to date recommendations and medical advice.

<table>
<thead>
<tr>
<th>Age</th>
<th>Growth</th>
<th>Heart/Dental</th>
<th>Thyroid</th>
<th>Sight</th>
<th>Hearing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 6 weeks</td>
<td>Length/weight/head circumference - Plot on Down syndrome specific growth charts.</td>
<td>Clinical examination ECG + Chest X-ray At Birth &amp; 6 weeks. Or Clinical examination + ECG + Echocardiogram At Birth &amp; 6 weeks</td>
<td>Routine Guthrie test</td>
<td>Eye examination, to exclude Cataract &amp; Glaucoma</td>
<td>Neonatal screening Where available.</td>
</tr>
<tr>
<td>6 - 10 months</td>
<td>Growth assessment as above at each routine visit. Encourage healthy eating &amp; regular exercise at all times.</td>
<td>Early Dental Advice</td>
<td></td>
<td>Visual behaviour to exclude squint.</td>
<td>Full audiological review. (Otoscopy, Impedance, Hearing thresholds.)</td>
</tr>
<tr>
<td>12 months</td>
<td>Growth assessment as above at each routine visit. Encourage healthy eating &amp; regular exercise at all times.</td>
<td>Dental Advice</td>
<td>Full Thyroid function tests. Or TSH (Guthrie) (fingerprick TSH) yearly when available.</td>
<td>Visual behaviour to exclude squint.</td>
<td></td>
</tr>
<tr>
<td>18 - 24 months</td>
<td>Growth assessment (height/weight) as above at each routine visit. Encourage healthy eating &amp; regular exercise at all times.</td>
<td>Dental Advice &amp; Examination of teeth</td>
<td>Full Thyroid function tests. Or TSH (Guthrie) (fingerprick TSH) yearly when available.</td>
<td>Ophthalmological examination including Orthoptic screening, refraction &amp; fundal examination.</td>
<td>Full audiological review. (Otoscopy, Impedance, Hearing thresholds.)</td>
</tr>
<tr>
<td>3 - 3½ years</td>
<td>Growth assessment (height/weight) as above at each routine visit. Encourage healthy eating &amp; regular exercise at all times.</td>
<td>Dental Advice &amp; Examination of teeth</td>
<td>Full Thyroid function tests. Or TSH (Guthrie) (fingerprick TSH) yearly when available.</td>
<td></td>
<td>Full audiological review. (Otoscopy, Impedance, Hearing thresholds.)</td>
</tr>
<tr>
<td>4 - 4½ years</td>
<td>Growth assessment (height/weight) as above at each routine visit. Encourage healthy eating &amp; regular exercise at all times.</td>
<td>Dental Advice &amp; Examination of teeth</td>
<td>Full Thyroid function tests. Or TSH (Guthrie) (fingerprick TSH) yearly when available.</td>
<td>Ophthalmological examination including Orthoptic screening, refraction &amp; fundal examination.</td>
<td>Full audiological review. (Otoscopy, Impedance, Hearing thresholds.)</td>
</tr>
</tbody>
</table>

From Age 5 to Age 19 Years

| Paediatric review | Every year |
| Cardiology | Echo in early adult life to rule out mitral valve prolapse |
| Hearing | 2 yearly audiological examination (Otoscopy, Impedance, Hearing thresholds.) |
| Vision | 2 yearly ophthalmological examination including refraction and fundal examination. |
| Thyroid | 2 yearly from 5 years (venous) or annual fingerprick TSH, when appropriate structures, personnel & funding are in place. |
A selection from Woodbine House on Down’s syndrome issues.

www.woodbinehouse.com
for a full selection.

New 2006 DVD

New 2004 DVD

New 2006

New 2006

New 2006 DVD
I. Neonatal Period
(birth -2 months)

A. History
1. Parental Concerns
2. Feeding Pattern
3. Stooling Pattern

B. Physical Examination
1. Complete general physical and neurological examination
2. Plot height and weight on Down syndrome growth chart
3. Look for signs of congenital heart disease such as cyanosis, irregular heart rate, or heart murmur
4. Careful examination for otitis media and cataracts
5. Screen hearing

C. Lab
1. Karyotype
2. Thyroid function (THS)
3. Echocardiogram (SBE)
4. Auditory brainstem response (ABR)

D. Consultation
1. Cardiology
2. Genetic

E. Recommendations
1. A follow-up appointment at a Down syndrome center
2. Parent and education support by referral to local and national parent support group
3. Referral to infant education program (Early Intervention)

II. Infancy
(2-12 months)

A. History
1. Review parental concerns
2. Review medical history, especially in relation to otitis media and constipation

B. Physical Examination
1. General physical and neurological examination
2. Plot parameters on Down syndrome growth chart

C. Lab
1. Audiology assessment
2. Thyroid screening that includes T4 and THS at one year of age

D. Consultation
1. Cardiology
2. Infant development specialist or team of occupational therapist, physical therapist, and speech and language therapist
3. Ophthalmology syndrome center
4. Nutritional where indicated

E. Recommendations
1. A follow-up appointment at a Down syndrome clinic
2. Continue appropriate education and intervention programs
3. Continue family education support
4. Regular exercise and recreational programs
5. Discuss respite care with family

IV. Adolescence
(12-18 years)

Same outline as 1-12 years with the following additions:

A. History
5. Inquire about symptoms of hypothyroidism

C. Lab
5. Echocardiogram where indicated for mitral valve prolapse
6. Repeat cervical spine film at 18 years of age

D. Consultation
6. Pelvic exam and Pap smear for teenage girls

E. Recommendations
6. Continue appointments at a Down syndrome center
7. Review educational and transitional vocational plans
8. Sexuality education

Source: National Down Syndrome Congress, USA
In North America there are over fifty Down Syndrome Clinics. Some are bigger than others, but the best clinics have a Children’s Hospital as a base for operations and they serve about 2,000 children who have Down’s syndrome. Parents want this service and travel hundreds of miles to a clinic appointment. Usually they get a referral from their doctor. Clinics are staffed by medical professionals with a special interest in Down’s syndrome. The hospital provides access to specialists and diagnostic equipment. So this becomes a one day trip for a full evaluation. There is a thorough healthcare check-up and they look for problems that may cause delayed development and problems later in life.

In the USA some of these clinics have become CENTRES of EXCELLENCE for Down’s syndrome. Mental health issues are getting much more attention because there is a higher incidence of these problems. When our children become adults mental decline is a big concern. This is where Down’s Syndrome Clinics excel, and have the potential to achieve so much more for our children. New therapies and medicines to prevent these problems must be started early, research is very important and needs big numbers.

In the UK there are about 600,000 babies born each year. About 700 of these babies are born with Down’s syndrome. There are about 300 Primary Care Trusts (PCTs) around the UK, each PCT must fund the services needed by patients in their area. On average two babies with Down’s syndrome will be born in a PCT each year. Fortunately many of the health issues can be treated by experts in each of those areas. Paediatricians develop an interest in Down’s syndrome but there are not nearly enough babies born in each PCT to develop a lot of experience in Down’s syndrome health issues. What is needed is a few centres where some real expertise can be developed and hundreds of children and adults with Trisomy 21 can be seen each year. This will allow us to learn a great deal more and we can conduct research into important health and development issues at the same time. Especially the very important research into Demential and Alzheimer’s disease.

Want to learn more?
Watch and listen to the experts who created a Down Syndrome Clinic from scratch.
Send us a stamped self addressed large envelope - Tell us what you want.
We will send you this Free DVD.
Become a DSRF-UK member. (No charge)
**Down’s Syndrome Clinic**

This comprehensive clinic is in Baltimore, USA – It is one of the best there is

---

**Mission Statement**

“Children with Down’s syndrome are children first, each a unique person with individual strengths. The Down’s syndrome Clinic Team is committed to working with you to help your child or adult family member reach his or her full potential and function as independently as possible in all aspects of family, school, and community life.”

**A Unique Service**

At a single location, the Kennedy Krieger Institute offers unique, multi-disciplinary, and comprehensive services for children, adolescents, and young adults with Down’s syndrome, including:

- initial follow-up evaluations
- preventive medical screening
- medical consultation
- parent training
- on-going therapy

---

**The Down’s Syndrome Team**

Down’s syndrome is associated with a variety of medical conditions and delays in many aspects of development and function. Therefore, it is important for parents, health care professionals and teachers to have a clear and accurate understanding of each child’s medical problems and level of developmental functioning. Our team can provide this information and the following services:

**Medical**

Certain medical conditions frequently associated with Down’s syndrome can cause health problems and slow developmental progress. Certain conditions may become evident during the first few years of life; close monitoring is especially warranted during this period. The developmental paediatrician will provide:

- a comprehensive neurodevelopmental examination
- preventive medical screening
- medical consultation for specific concerns
- recommendations for parent education
- evaluation of adults

---

**Physical Therapy**

Young children with Down’s syndrome will learn to roll over, sit, crawl, stand and walk. After they master walking, they can learn to run, climb stairs, jump and ride a tricycle. The physical therapist will help your child to achieve each gross motor milestone, while providing the following:

- assessment
- home programs
- parent training

---

**Occupational Therapy**

Occupational therapists help facilitate skill development with emphasis on:

- arm and hand use
- safe and appropriate feeding skills
- increasing independent participation in daily living activities

---

**Audiology**

Hearing loss occurs more frequently with Down’s syndrome. A hearing loss in young children may affect speech and language, cognitive, behavioral and social development. An audiologist can:

- evaluate hearing
- diagnose hearing loss
- monitor middle ear ventilation tube function
- fit hearing aids, when necessary

---

**Want this ~ Free DVD ?**

Send a Stamped Self Addressed Large Envelope
Tell us what you want
Become a DSRF-UK member

---

*bright beginnings 16 newborn parent guide*
**Speech and Language**
Down's syndrome patients typically have delays in speech, language, and communication skills. These communication problems may cause a reduced ability to understand language, weakness in functional communication skills and/or behavioural difficulties. The speech-language pathologist will work with you to:

- develop a profile of your child’s speech, oral-motor, language and communication abilities
- formulate recommendations to help maximize your child’s language and communication potential
- provide parent training

**Behavioural Psychology**
Parent training, behavioural consultation and treatment are available for individuals with a wide range of behavioural difficulties, including: non-compliance, tantrums, aggression, self-injury, incontinence, communication deficits, and social skills deficits.

Services are generally provided in the clinic, home, school and other community settings.

**Clinical Psychology**
The developmental assessment of school-age children may include a psycho-educational evaluation in order to identify specific strengths and weaknesses. This may be necessary in helping to formulate goals for your child’s individualise education program (IEP) and to ensure an appropriate educational curriculum.

**Genetic Counselling**
Counselling is available upon request to all families and couples planning to have more children.

**Social Work**
A child with Down’s syndrome has an impact on the entire family. Since each family copes differently, all new families are seen by our social worker to provide:

- referral to community resources and parent groups
- assistance with transitions and life-care planning
- individual and family counselling service (upon request)

---

**Down’s syndrome research priorities for Alzheimer’s and Dementia**
We urgently need Centres of Excellence for healthcare and for research.

In the UK we don’t have these “Centres of Excellence” for Down’s syndrome. There are 700 births a year in the UK and this is 20,000 patients under age 30 who really need to be followed during these years in order to deliver the best healthcare to suit their needs and to conduct important research to speed the design of medicines for this population. There are a few doctors who have a special interest in Down’s syndrome but an interest does not constitute a program to do the amount of research needed in the UK. We need a medicine now to help the thousands of patients with Trisomy 21 we have the technology - now we need the commitment!

Research into Alzheimer’s has a very high research priority for the General Population but it is very difficult to do research for this population when you cannot know those patients who are most at risk. A cure is not possible when the brain has been damaged. A medicine must prevent this happening. Patients with Down’s syndrome are at high risk and need that medicine even as children. Centres of Excellence for Down’s syndrome research can become the key to discovering the biochemistry that leads to the design of these new medicines they need and we need those same medicines as we all live longer and we are at risk of Alzheimer’s.
The search for a medicine for Down’s syndrome.  

By Peter Elliott  
(DSRF-UK Research Director)

A recent survey in the USA - parents were asked how they felt about the new research underway that promised a breakthrough in the development of a medicine to help children with Down’s syndrome. The reporter was surprised when many of these parents said they did not want a medicine. This became a news story that swept across the USA and it is pretty damaging to all of the research underway to help our children. Parents need to understand why we must do this research. (And volunteer to donate tiny blood samples for this research.)

Some parents feel they must accept Down’s syndrome as an integral part of who their child is. Down’s syndrome is a medical diagnosis (it’s not what your child is). You don’t have a Down’s syndrome child, you have a child who has Down’s syndrome, and Down’s syndrome is caused by Trisomy 21 (T21). These are normal children with a few extra genes and those genes are also normal genes.

What parents don’t understand is the genes are changing their expression thousands of times every minute of our lives and billions of genes will turn on and off in response to changes in the biochemistry and alter the way our various parts of the body are very efficient or perhaps inefficient and when the genes change their expression this changes the biochemistry throughout the body and the brain. This is a very dynamic and inter-active activity and it controls every aspect of our life including our health and growth years and our development throughout life and our ability to fight diseases and regenerate new parts of our body that become damaged or just wear out. This is the new field of research where we need to design medicines that interact with the biochemistry and control the expression of the genes to make them function more normally.

This is the science of epi-genetics and all medicines in the future will be designed to control our epi-genetics by influencing our biochemistry.

What offers a great deal of hope for our success is the fact that our children with Trisomy 21 are so very normal, and most of the time so very healthy. But we can see differences and when these differences effect the brain we must regard this as a very serious problem that urgently needs a medicine. Presumably it is the extra T21 genes that cause these differences but those genes may be influencing thousands of other genes. We can now see that is happening and we can see the biochemistry is very different from what it should be. So the next challenge is to test medicines to correct the biochemistry and these medicines will probably be based on very safe micro nutrients found in food but not at the high levels needed to make a medicine. So we need to test these to arrive at the right dose rates and the correct nutrients.

So a whole new world of opportunities lie before us and we can think in terms of medicines to correct health and development problems that are called “Down’s syndrome” and which are caused by “Trisomy 21”. And this includes improving their memory which is impaired by a chemical imbalance we believe can be corrected and of course we want to prevent brain degeneration seen in these adults that is linked to Alzheimer’s. These are research objectives that parents can support and not be afraid.

Want to get more involved supporting our research ?

You could start by getting parents to join the DSRF-UK

Then do fundraising specifically for research.

The DSRF-UK is the only UK registered charity with this medical research objective. Its what we do !
Can Brain Function really be improved?

Prof William Mobley is the Chair of the Department of Neurology and Neurological Sciences at Stanford University in San Francisco. He runs the Down Syndrome Research and Treatment Center at Stanford and they are conducting some of the most advanced research in the world to understand the human brain and the Down’s syndrome brain. His presentation was wonderful and had the audience captivated and hushed. Although the subject is very complex it can be understood by most parents and his closing statement that he expects to have a therapy to improve and enhance brain function within the next 5 years was a complete surprise. You will want to watch this video. (See DVD 3.)

Why do Trisomy 21 pregnancies happen?

Dr Jill James has conducted research to look at blood samples from mothers who had just had a baby with Down’s syndrome and discovered homocysteine levels significantly higher than normal, suggesting that there may be genetic or metabolic risk factors. (DSRF Note: Homocysteine is often elevated as we grow older and this correlates to a higher incidence of Down’s syndrome births in older mothers.) More research is needed, but any women who is planning to get pregnant should ask their GP to check their homocysteine level several months before getting pregnant and get their homocysteine level down to safe low levels, as a precaution.

This important information is on DVD 2.

Research within a Down’s syndrome Clinic.

Dr Capone and his team are committed to research that explores the neurological basis of cognitive impairment and co-morbid psychiatric disorders associated with Down’s syndrome as well as the genetic basis of congenital heart disease. These activities help to increase our understanding of Down’s syndrome and have the potential to produce new treatments. He links them to autistic spectrum disorders in children age 2 to 10 years. Dr Capone runs the clinic described in pages 16 & 17, and he has also helped to establish new clinics around the USA. His clinic conducts research and this is the model he advocates. (See DVD 2.)
You will have them all right. You may wonder if you are losing your mind. Probably not. But strange times will come, and getting through them takes energy and courage.

Some experts have described in detail the stages you are expected to face. These stages are similar to the grief stages faced in the death of a loved one. The only trouble is that parents who are adjusting to children with disabilities do not follow a set course. Each parent reacts differently.

Here are a few oversimplified descriptions of stages you may or may not experience. Many parents could add to this list:

THE DRAGS
You feel so tired you can hardly drag yourself around. The sun may be shining, but to you the day seems cloudy. You may feel a lump in your throat or knots in your stomach. It is hard to breathe, and every once in a while you may hear yourself sighing. You may even wonder if you have the flu. When these times come, you wish you could find a warm cozy hole, crawl into it, and close a lid after you.

THE SPEEDS
When this stage approaches, you feel as though somebody has wound your spring too tight. You can’t concentrate on any one thing for more than a few minutes...there is just too much to think about!

So many places to go
So much to do
So much ground to cover
So many people to see

Many new ideas and concepts needing to be acted upon come to your mind. It is your personality’s way to “get at it” even if some motions are wasted. You become edgy, and nervous. You walk the floor or lie awake in bed all night tossing and turning.

Consider this option: When the speeds come on, stop. Sit down for a moment. Then talk slowly, walk slowly. Pick only one of the 241,000 things that you feel you should do that day, and do it.

THE BLOCKS
Tough news came from the doctors. But somehow your ears refused to hear what they told you, and your eyes remained blind to the evidence they presented. The knowledge that your child possesses a disability is hard to take. You may even talk to others as if your child has no disability. This is OK for a while. Parents’ minds need time to change from believing their child’s a “super baby” to seeing that child as he or she really is. It is all right to make this shift slowly. But it is unhealthy if it is never made.
THE HURTS
No professional can describe all the types of anguish and pain parents feel. Nevertheless, all of them hurt; they hurt badly. Bear in mind that when you do feel this pain, it may be your body and mind saying to you that you are strong enough to bear the hurt you must feel. Allow yourself to feel all that you must. You will never suffer pain beyond what you can endure. There are many mechanisms within you to dull the senses when things become overwhelming. Some people can become stronger from enduring pain.

If you happen to be hurting while reading these sentences; the purpose of this article is to help you grow and adjust so that you can accept, love, and act creatively on behalf of your child. You cannot do this without experiencing some hurts, enduring them, and working your way through them.

THE GUILTS
At times you may feel you have committed some horrible sin. You may even look deeply into your past, searching for that single horrid act that caused it all. Somewhere, somehow, you committed an unpardonable sin, and now you are paying for it. On some days you feel sure that you must be the worst person on the face of the earth. Please remember that it serves no purpose for you to drag out all the black things in your life examining them one by one. This exercise only gets in the way of adjusting to your child. Learn to admit to yourself that no matter how real these feelings may seem, they are strange and irrational. They will pass.

THE GREATS
While a few days earlier you may have felt that you were the world’s worst mom or dad, now it may come to you that you are one of the greatest. You secretly may feel that God has chosen you to bear this extra burden because you are more special than others. Of course, it is more pleasant to fantasize yourself as being great. It is better than feeling you are the world’s worst. SO enjoy it while you can. But be careful. Sooner or later somebody will say or do something to send you crashing off your pedestal. When that happens, it is to be hoped you will not fall into the guilt trap again. Instead, you may achieve a fresh stability from knowing you are not a “super parent.” You have your weaknesses and strengths, like everyone else.

THE HATES
After hurting for a time, you may search irrationally for chances to blame others and hurt them. Almost anybody you can think of may be a target:

Your spouse
Your neighbour
Your doctor
Your Minister
Your children
Your parents or in-laws

So you watch and wait. Sooner or later, someone will say or do something to “justify” unleashing your anger at them. Fortunately, your gracious friends and relatives often remain unruffled when you blow your stack at times like these.

It is all right to feel such anger and hatred, even though it is irrational. Acting on that anger, however, can be dangerous. It could make others hurt...then you hurt because you cause them pain...and the vicious cycle starts over again.

Do not blame your doctor. The news that your child has a disability will hurt no matter how he or she breaks the news to you. On the other hand, if your physician, in relating to you and your child, develops irrational blocks, get yourself another doctor.

Sometimes when you awaken at 2:00 A.M., you may wish you could close your eyes and never open them again. These wishes usually will remain secret because you will be ashamed of them. Nevertheless, many parents of children with disabilities openly confess to going through stages when they felt such an urge to escape. In spite of such in-the-wee-hours-of the morning urges, hang on. By the time the sun rises, the situation often looks brighter.

Adapted from an article by Robert Perske

Parent Perspective

“The news that our new baby had Down’s syndrome seemed almost unreal, like I was dreaming, and I half expected someone to come wake me up and tell me our baby was actually just fine. My husband and I didn’t cry in front of the nurses or the doctor. We just gulped, ‘OK,’ when they told us about the Down’s syndrome, and tried to process the bewildering news. When we were alone in our room, we held each other and sobbed. We were so scared! We couldn’t even hold our baby who was all hooked up to wires and monitors. The social worker watched us so closely, probably expecting us to have an emotional breakdown right there in front of her. By day two, we had come to grips with reality, and decided to deal with everything in an optimistic way. It was actually not too hard – our baby was adorable! I think the social worker thought we were in some sort of denial because we weren’t grieving and crying. We just got over the shock quickly. Everyone is different in dealing with the news their baby has Down’s syndrome. It may take them months or years to get over the negative feelings. Or, like us, it may take just until you finally get to hold your precious little one for the first time.”

“I have to admit that at first the news was devastating. But after a week or so, we realized our ‘imagined reality’ of Down’s syndrome was much scarier than everyday life with our sweet little baby. We got tired of well-meaning friends, and even family, who kept on offering condolences. We had a new baby and we wanted people to say, ‘Congratulations!’ instead of ‘We are so sorry,’ expecting they needed to comfort us or something. I really appreciated the people who were happy for us.”

adapted from an article by Robert Perske

Parent Perspective

“The news that our new baby had Down’s syndrome seemed almost unreal, like I was dreaming, and I half expected someone to come wake me up and tell me our baby was actually just fine. My husband and I didn’t cry in front of the nurses or the doctor. We just gulped, ‘OK,’ when they told us about the Down’s syndrome, and tried to process the bewildering news. When we were alone in our room, we held each other and sobbed. We were so scared! We couldn’t even hold our baby who was all hooked up to wires and monitors. The social worker watched us so closely, probably expecting us to have an emotional breakdown right there in front of her. By day two, we had come to grips with reality, and decided to deal with everything in an optimistic way. It was actually not too hard – our baby was adorable! I think the social worker thought we were in some sort of denial because we weren’t grieving and crying. We just got over the shock quickly. Everyone is different in dealing with the news their baby has Down’s syndrome. It may take them months or years to get over the negative feelings. Or, like us, it may take just until you finally get to hold your precious little one for the first time.”

“I have to admit that at first the news was devastating. But after a week or so, we realized our ‘imagined reality’ of Down’s syndrome was much scarier than everyday life with our sweet little baby. We got tired of well-meaning friends, and even family, who kept on offering condolences. We had a new baby and we wanted people to say, ‘Congratulations!’ instead of ‘We are so sorry,’ expecting they needed to comfort us or something. I really appreciated the people who were happy for us.”

adapted from an article by Robert Perske
She laid there such a helpless little scrap, her wispy red hair in a funny little crew cut, her little eyes slanting upward. She touched my heart.

Our baby Tamara is now 17 months old. She is incredibly happy and loving, as Down’s syndrome people most often are. She has brought with her so much love and joy. She has changed our lives. Ours is a much happier family since she joined us; we will be indebted to her forever.

Written by Imogen’s Mum, Diane Whiteside
Christmas 2004

I picked her up, I felt as though she would slip right through my arms. To learn to feed her was a difficult task; the bottle teat would always find its way under her curled tongue. I smiled as I put a tiny nappy on her as it came up to her armpits. It was hard to leave her that first day but I felt so elated. I went back the next day, tended to her and cuddled her. The third day I was allowed to take her home.

Philip and Sally’s little faces lit up as I met them at school with this tiny baby I had told them so much about, and Natalie got home from her school faster than I had ever known!

We didn’t call the baby Leanne very often. We called her ‘chickenpie’, ‘sausage’, ‘dumpling’ or just ‘baby’, as we would choose her name if we were approved to adopt her.

The waiting was so awful, we loved this tiny baby so much already, that we couldn’t bear to think of just fostering her until someone else came along to look after her for the rest of her life. We love her more each day and vie with one another for her attention.

We watched her grow and learn; each task she achieved brought such applause and praise from us and the more we helped her the more she learned. Then the day came when baby was five months old we were told we could be her forever family. We couldn’t conceal our happiness; we walked around, faces beaming for all the world to see. By this time baby was at the stage in her development where she grasped at things, so we wrote three names; Cassandra, Imogen, and Tamara, and put them into a hat. She put in her tiny little fist and plucked out Tamara then she plucked out Imogen. So now she has a name at last.

Another wonderful 5 months went by; Tamara still stealing everyone’s attention, still stealing hearts, still learning new skills.

Then the day came, that will stay in our minds forever. The judge put on his robes and his wig for the children, and smiling he chatted individually to Natalie, Philip, Sally and myself. Then smiling broadly, he said:

“I am very happy to tell you, Tamara Imogene is now legally yours”.

Our special baby
Our second daughter Hayley was born on the 10th February 2002. She was 6 lb, healthy, pink and quickly made herself known and started to feed. She also has Down’s Syndrome (DS), a fact that became known to us before she was born at around 20 weeks of pregnancy after a scan and an amnio test. As a result of knowing about the DS, the whole family had a head start to deal with it. We quickly became lay experts and although it was a difficult time, the subsequent benefit for us (especially myself) has been enormous. We feel very fortunate that we had a chance to come to terms with the situation before she arrived with all the force of her personality!

Hayley is nearly two – and is no more an easier toddler than she was an easy baby. She never slept well and seems to have the ability to survive on just a few hours at a time (just as her older sister did!), which is very very hard for Mum, as her one source of comfort seems to be breastfeeding. Being attachment parents, we are keen to continue the breastfeeding but its hard for mum.

Hayley makes it clear what she wants – pointing, trying to say things and yelling when anyone dare leave her waiting for a minute! She has started climbing everything she can much to her amusement and her parents trepidation. She has some Makaton signs but also makes do with a point and a word that we are sure is ‘this’ – pretty much a catch all. She is very experimental with all foods and has no need for a spoon when she has her fingers, nor plate when she has her face and hair!

She worships her older sister, Rachael, and the feeling is reciprocated. They are clearly each others favourite people and sometimes Sue and I look at each other and know that we are possibly in big trouble when they get older, but at the same time it makes us so proud.

Rachael understands Hayley has special needs – speech therapy and physio. She understands that Hayley is small for her age and will always be so. She understands that Hayley will learn everything that she wants to learn and that it will be slower than she herself learned things. She also intuitively knows that it does not matter to their relationship and probably never will in anything other than a ‘my annoying younger sister’ type way. Hayley should never burden Rachael and visa versa.

We have high hopes for both girls – and they are not that different. We want them to be happy and well adjusted, to find a place in society, to maintain loving relationships. Of course, all our hopes for grandchildren rest with Rachael, and that’s the major difference – I will worry about that later. I have learned that the Down’s does not seem to be as much of a problem at any stage as I always think it will be.

We are not idealists and understand that Hayley will face prejudice and difficulty, and some people with have old fashioned views based on fear and lack of understanding. She may encounter health problems and will have challenges to overcome just to achieve things that we consider normal – money, travel, work, relationships. I am very concerned about bullying and my own reaction to it. I will cross these bridges as needed – she is two and I am just enjoying her. Some people will see her as a burden to us and perhaps even to society, but she will almost certainly grow up with an innocence and outlook on life that will be something to be envied. She is blessed with a sunny disposition on life that I find continually charming.

I also know that she will be loved and continue to love. She will also have Down’s Syndrome, but this will not define her to the people that know and love her (usually the same thing!)
what about my other children?

Siblings may benefit from meeting with
If you have other children in your family, you may want to keep the following in mind:

As soon as you understand the diagnosis of your child with special needs, try to explain it to your other children. Keep it simple. Answer their questions honestly.

If your child with a disability is in a hospital or special program, take your other children to visit the hospital or program. The more your children understand and learn about their brother or sister with special needs, the easier it will be for them to accept the baby’s condition.

You may find that your other children are having some of the same feelings about their brother or sister that you are having. These feelings may include shock, guilt, anger, confusion, embarrassment, or sadness. Talk to them often about how they are feeling.

It may be that your other children have none of the feelings listed above; instead they may be confused that when all they see is a cute new baby, others are primarily seeing the disability.

Siblings may benefit from meeting with and talking to others who have a brother or sister who has special needs.

Because babies and children with disabilities have needs demanding a great deal of parents’ time, be sure to do something special with your other children as often as you can. They need your attention, too.

Your other children may be willing to help you in many ways with your child with special needs; however, do not give them too much responsibility in caring for their brother or sister with a disability. This may cause resentment to grow.

Share your feelings with your other children that your child with a disability makes you happy and proud. They need to feel the joy and happiness that is possible in having a child with special needs in their family.

Parent Perspectives

“A month or two after our son was born with Down’s syndrome, I was asked if I’d go visit another parent who had herself just given birth to a son with Down’s syndrome and who needed someone to talk with. As we got in the car to leave, my ten-year-old son asked me where we were going. When I explained that there was another family who was sad and their baby had Down’s syndrome, my son replied, ‘Oh. So why are they sad?’ This was an important lesson to me that children are much more accepting than we think.”

“In many cases, it’s the child with Down’s syndrome who gets all the attention from friends and family. My relatives are always inquiring, ‘How’s our special girl these days?’ After answering their question, I always try to add that my two girls are doing fine as well.”

“One of my friends has two children with Down’s syndrome, and then one in between who doesn’t. When I first met their family, I shook the hands of the two with Down’s syndrome, and then the one in the middle, who told me his name and said with an irritated sigh, ‘And I DON’T have Down’s syndrome.’”
Children learn a lot from each other, and this starts very early in life: “...pre-verbal babies can take home with them what they learn from other babies,” said Andrew Meltzoff, Developmental Psychologist at the University of Washington.

He conducted studies with 128 toddlers, which showed they have a remarkable ability to learn from each other - and; “...what they learn in a group is retained outside of the group setting.” An article on his findings appeared in the July 1999 issue of the Journal of Developmental Psychology.

The key to this learning experience is - INCLUSION.

We are told that our children are “Special”. But all children are special and all children need to have fun and play together. Our children want to play with children in the neighborhood and make friends. They want to be invited to birthday parties and be invited to play with children having fun. They will learn a great deal if you allow this to happen. Look at these children, you can see their brains are working overtime. But one little boy is not included. Do you get the impression he is really interested and wants to make friends?

Children can be of mixed abilities and at various stages in their development. They need not be in school and it is best if adults (and experts) are not involved.

Children are not impatient with each other, they are persistent and they investigate and they learn and then they communicate with each other. This kind of learning is remembered because it is fun. Experts believe children invented language. Then taught parents those communication skills thousands of years ago.

Our children have difficulties with memory. This is not their fault. Stress makes matters worse. Information learned at play is stress free and it will be remembered. The human brain has a reward system that kicks in when we are happy and relaxed and this is the key to improved memory and mental abilities.

When we talk about early intervention we should think about what is natural and what has worked for all of human history. This is how INCLUSION works. Special play groups where all the children have Down's syndrome are unnatural and this is the opposite of inclusion. Our children need friends in the neighborhood they can go to school with. They want acceptance.
Are there some things that you would never do? 

Take flight in an ultralight perhaps?

That little boy who wanted to play with the kids next door is now grown into a young man and here he is sitting in the back seat of an ultralight plane. Was he scared to go up? You bet he was. He changed his mind at the last minute, and said: “After you Mom”. To my amazement, Mom went up first. In seconds that little plane jumped off the ground and it was a dot in the sky. It scared me just watching.

After his Mom landed David decided to take a flight. Here he is after he landed. Proud of himself he had both hands in the air.

What can you learn from this? Well for a start you can know our kids are brave in the face of danger and they can decide to do things that any crazy teenager might decide to do just for a thrill.

So don’t assume they are limited or that they cant do something. They can know something is dangerous and still decide this is something they want to do. But David’s reading is rudimentary and his math is hopeless. So he is still learning these things while mastering other things like riding a bike.

What is the most difficult thing we learn?

We learn to communicate, this is a huge achievement and it sets us apart from every creature on earth. In our case we learn to speak English and this is a very complex language. Babies and very young children learn to understand language and to speak that language because they enjoy pleasing their parents. They quickly realise it gives us pleasure and they get smiles when they say some words. The feedback is immediate and they feel safe and happy. This is the kind of feedback that improves memory and the brain provides chemical feedback to make these memories. Fear and worry does the opposite. Many words are remembered and they are connected to people, places, things and actions. There will be many clues to the meaning of a word so the children remember these words more easily. Apple is just a noise until it gets in your mouth as food and it is tasted, every mother will tell the baby what they are eating. Mom even tells the baby it tastes nice. So here you have the best example there is of early intervention and mothers and fathers and brothers and sisters are the experts providing that early intervention. Not another expert to be seen anywhere. And you teach the most difficult thing we will ever learn.

Why children can’t read.

We have information on our website www.dsrf.co.uk Learning to read is a big problem for all children. We teach the alphabet and assume this is helpful but it is just confusing. A-B-C-D-E sounds Ay, Bee, Cee, Dee, Eee. But in reading it’s different, A-B-C-D-E is Ahh, Bu, Cu, Du, Eh. Letter combinations are like a secret code. It’s really insane but it is what we are stuck with. The human brain is so powerful that after a number of letter combinations are memorised there is an intuitive leap and we start to recognise those pictures of letter combinations and we connect them to the sounds of speech and then we can read. But what happens if you have a problem with memory and can’t remember those pictures of letter combinations or the sounds they make. Then you can’t read and by the time this happens the class has moved on and a few children are left behind and some of these children will have Down’s syndrome.

See this program on-line at www.readamerica.net/britain.asp?link=specialists

Everyone Counts is a program for schools that is designed to:

* Increase Teacher & Student understanding of Down’s syndrome and other cognitive disabilities.
* Promote acceptance & Inclusion of individuals with Down’s syndrome and other disabilities.
* Foster inclusive attitudes by celebrating diversity and individuality.

This program uses fun, straightforward lesson plans and activities to encourage positive relationships between students with or without disabilities. The curriculum’s engaging video is an adaptation of the popular children’s book ‘My friend Isabelle’.

Three 60 second vignettes produced by Nickelodeon teach kids that we are all different - & that’s what makes us all the same!
Aidan’s
I think it’s serendipitous that my second son’s birthday is so close to mother’s day. When Aidan arrived, I had already been a mother for more than three years. My first son, Timmy, a strong-willed, inquisitive boy had taught my husband, Phil, and me many things—like how to survive on four hours sleep, the best ways to navigate through a tantrum, and how to hide vegetables in chili. But I don’t think I came face-to-face with the true range of what motherhood means to me until Aidan entered our lives eighteen months ago.

It was the first hot day of spring when Phil and I checked into the hospital. Shortly thereafter, Aidan came into the world looking very much like his brother, howling, arms and legs flailing, a mop of wild hair matted to his head. But when the midwife handed him to me, I looked right into his tiny face and stopped for just one instant. Hmm, I remember thinking, his eyes look a little strange.

I quickly rejected that thought—no, everything’s fine—and turned to Phil. We reveled in the afterglow of what had been an easy birth, and talked about how lucky we were. We were filled with gratitude for the beautiful family we had created, and looked forward to getting home and starting our lives together.

Then the nurse arrived to tell us that she needed to send the baby to the nursery because he was a little cold and they wanted to warm him up. She took him away, and we began to call family and friends to share the good news about our 8-pound 13-ounce newborn son. But when Aidan still hadn’t been returned an hour later, I had a nagging feeling that something was wrong. I didn’t want to ruin the moment—or lend weight to my fears—so I said nothing to Phil.

The midwife arrived. She told us that there was a possibility our baby had “chromosomal problems.” I refused to let it sink in. Oh, a chromosomal problem, I thought. I’m sure they can fix it. Although my mind hadn’t registered her meaning, my body must have because a chill ran right to my neck. Phil was silent. Maybe one of us asked what she meant exactly. Maybe she spotted our look of obvious misunderstanding. So she spelled it out: “The nurse thinks he may have Down’s syndrome.”

From where I sit now, I can split my life in two. There’s the time before we heard those words, and the time after. Before, we were probably like most people. We knew we were lucky. We were healthy. Our little boy, Timmy, was funny and strong and happy. We had jobs and a loving family. But until we were hit with those words, I don’t think we had any idea how fragile that luck can be.

I knew nothing about Down’s syndrome, but I had lots of frightening preconceptions. My first thought, even as I nursed him in the hospital, was, “How will he get a job?” My instinct right from the start was to hold him tightly against a world that seemed irreversibly changed.

I thought back on my pregnancy, which had been uneventful. Because I was over thirty-five, my doctor had advised me to have an amniocentesis. So I’d made an
appointment for the prenatal test that was to determine whether my baby had a chromosomal abnormality or spina bifida. I got as far as the ultrasound. Just before the doctor started the test, I changed my mind. I told the doctor I didn’t want to risk a miscarriage.

“Well, your chance is one in a hundred that you’ll have a baby with Down syndrome,” she said. “I’ve had ninety-nine other women in here this month and none of their babies had Down syndrome. You might be the one.”

I had been ambivalent about the amnio from the start. Driving to the appointment, I’d told Phil that I didn’t want to terminate the pregnancy no matter what the amnio revealed, and he’d agreed. We’d planned to have a second child, and there was no going back.

“Even if the baby has Down syndrome,” I told the doctor, “I won’t terminate the pregnancy, so what difference does it make?”

“Well, that’s what everyone says,” she told me. “But they change their minds when they get the test results.”

I was offended by her flip attitude toward my baby. “Well, I’m not changing mine.” And we left, clutching the ultrasound photos of our beautiful baby.

Now here I was five months later, holding my blue-eyed baby who suddenly seemed so distant. We took Aidan home and waited a week for the blood test that would tell us for certain whether the doctors’ suspicions were correct.

Meanwhile, we stared at him wondering. We compared him to pictures of Timmy as a baby. And we went back and forth with each other: Did he look the same or different? And were the differences we saw a result of Down syndrome, or because he was a different person? I kept thinking about the moment he was born, when I’d noticed something odd about his eyes. But other times I’d reassure myself that he was no different from Timmy, that everything would be fine. It was an agonizing period.

By the time the results were in, I thought I’d resigned myself to the worst. But the news sent me reeling. I cried for two days. I was grieving for the baby we had expected, the only one we thought we were prepared for.

When the tears dried, I began the long learning process that will continue, I imagine, for the rest of my life. Having resolved to find out everything I could, I went online, I read books, I talked to people. I was surprised to discover that everyone in the world, it seemed, was either related to, went to school with, or grew up next door to someone with Down syndrome. Everyone but me. I discovered an Internet support group for parents, and at the urging of one of them, I posted a message announcing Aidan’s birth. The fact that he had Down syndrome was understood. These parents wanted to know the truly important things, like our baby’s height, weight, and hair color, and their interest put
things into perspective for me.

Within days we had received more than fifty congratulatory notes, not one “I’m sorry” among them. Our spirits soared. Friends and family had been very supportive, but, let’s face it, they knew as much about Down syndrome as we had. And they were all a little sad, too. But these other parents weren’t sad at all. They felt their children were a great gift, Down syndrome or no.

As I poured over the books and talked with these other parents, I found the factual side of Down syndrome fairly easy to piece together. Also called Trisomy 21, it is caused when a person is born with three of the twenty-first chromosome rather than the usual two. This extra chromosome, and all its associated genes, alters the development of the body and brain. What this would mean for Aidan specifically would be hard to say, but he would be developmentally delayed to some degree (most people with Down syndrome fall into the moderate to mildly mentally retarded range) and would have low muscle tone. This would make it tougher for him to crawl, walk, and talk. The list of the other potential problems was daunting: heart defects, hearing loss, vision problems, small airways making children prone to upper respiratory infections, and on and on. In fact, it seemed that we spent the first few months of Aidan’s life in the offices of endless medical specialists, most with titles longer than our baby’s tiny body. By his first birthday, Aidan had seen a pediatric cardiologist, pulmonologist, ophthalmologist, audiologist, and an orthopedist, to name a few.

Of course, there was nothing in those reference books that could fully explain the other side of the story—the ups and downs of raising a child with Down syndrome in our society. That’s what we’ve been learning from Aidan himself, and it’s been a lesson filled with wonder. Aidan’s life so far has been more complicated than Timmy’s was.

There are more ongoing appointments—he has physical therapy, a playgroup, and a teacher once a week. There have been challenging days and frustrating moments as we’ve all struggled to learn about each other.

But we’ve come to recognize that we’ve had trying times with Timmy, too—they’ve just been over different issues. Timmy never slept. Aidan goes to bed at 7:30 p.m. and wakes up laughing. Timmy threw tantrums to beat the band; Aidan definitely knows what he wants, but he’s generally much less stubborn. We’re learning, as all parents discover with the birth of their second child, that each child presents a unique set of challenges.

Aidan is actually more like other kids than he is different. He will learn to walk, talk, read, sing, dance (you should see him rock to “Itsy Bitsy Spider”), although he will have to work harder than most kids do to reach those milestones. And we will have to slow down and allow him the extra time. Beyond that, he will have skills, talents, and quirks all his own. He already does. He scoots around the house using his bottom, two hands, and one foot faster than any crawler I’ve ever seen. He can find his Barney doll no matter how well we’ve hidden it. And he’s already using sign language, predating his eventual use of words.

When Aidan was newly born, all I could think about when I looked at him was “Down syndrome.” But now I see that the syndrome is just a small part of who he is and what he will become. Aidan has shown us that contrary to stereotypes, kids with Down syndrome aren’t always sweet angels. When he does get angry, he can throw a tantrum to rival his brother’s. When he doesn’t want to eat, he sweeps his vegetables off the table with a stubborn flourish. And he hustles away with a backward glance and a devilish giggle when he knows he’s put something in his mouth that he shouldn’t. Like the rest of us, kids with Down syndrome have a range of personalities, moods, and temperaments.

The future of people with Down syndrome is brighter than it has ever been, which makes me hopeful for my son’s adulthood. Early intervention, medical advances, inclusive schools that educate children all together, and new therapies have meant that people with Down syndrome can live longer, achieve more, and contribute to their communities in meaningful ways. Most of them graduate from high school; many live independently, marry, and have jobs. So while I wondered on Aidan’s first day of life how he would even find a job, now I dream about the possibilities. Will he love the theater the way his father does? Maybe he’ll want to work at a newspaper, as so many generations of my family have. Perhaps he’ll be wiser than his parents and find work that actually makes money.

It has been only a short time since Aidan came into our world. To a degree, we’re still on an emotional roller coaster. We have days of unadulterated joy over our family and what Aidan brings to us. And more wistful days when we wish that life were simpler, though these come less and less often. Sometimes I get sad about the might-have-beens, especially on the days when Timmy makes plans about the things he and Aidan will do together, and I wonder which of those dreams will come true. Many days I feel guilty and unsure as to whether we’re doing enough for Aidan. Would he be better off if we could afford this program, those vitamins, or that new therapy? And sometimes I get scared about what’s down the road, especially when I think of the struggles he may face making new friends in those horrible junior high years, or making his way in a culture that places such high value on convention and looks.

But as we head into year two of Aidan’s life, I’ve long since realized that our luck did not run out on the day he was born. Not at all. In many ways, our lives have been transformed. We have found loving support from people who used to be strangers. We look at the world differently and consider ourselves lucky to be able to. We have an appreciation for a slower pace; we take greater delight in each small step. And we have a newfound understanding of the preciousness of all people.

Valle Dwight, an editor for FamilyPC, lives in Florence, Massachusetts. This article originally appeared in Family Fun (Volume 7, No. 3) and is reprinted with permission from the author.

bright beginnings 31 newborn parent guide
Resources for Parents in the UK

**Your first point of contact** for any questions about the healthcare of your baby, should be your Midwife, GP or Health Visitor. A paediatrician or some other hospital-based specialist can also give healthcare advice.

**Other resources are:**

**Child Development Centres & Community Teams for Learning Disabilities**
These will consist of psychologists, speech and language therapists, doctors, etc., who can provide information and assistance. Your local GP surgery will guide you to one of these centres.

**Portage (www.portage.org.uk)**
Portage is a home-visiting educational service for pre-school children with additional support needs and their families. The aim of Portage is to support the development of young children’s play, communication and relationships and to encourage full participation in day to day life within a family and beyond the home. For more information or to find your nearest branch, visit their website: www.portage.org.uk

**Sure Start (www.surestart.gov.uk) 0870 0002288**
Sure Start is the Government’s programme to deliver the best start in life for every child by bringing together early education, childcare, health and family support.

**Parent Support Groups**
Parents share their experiences with each other and can often guide new parents to the services they need.

**Down’s Syndrome Association**
(www.downs-syndrome.org.uk) 0845 230 0372
Aims to help people with Down’s syndrome to live full and rewarding lives. They can help parents obtain DLA (Disability Living Allowance) for their child. And can help with appeals.

**Down’s Syndrome Educational Trust**
(www.downsed.org) +44 (0)23 9285 5330
Working to advance the development and education of individuals with Down’s syndrome.

**Down’s Syndrome Medical Interest Group**
(www.dsmig.org.uk)
Is a network of healthcare professionals, mainly paediatricians - from the UK and the Republic of Ireland. Their aim is to share and disseminate information about the medical aspects of Down’s syndrome and promote interest in the management of the syndrome.

**Contact a Family**
(www.cafamily.org.uk) 0808 808 3555
Contact a Family is the only UK-wide charity providing advice, information and support to the parents of all disabled children – no matter what their health condition. They enable parents to get in contact with other families, on a local and on a national basis.
“At our best level of existence, we are parts of a family, and at our highest level of achievement, we work to keep family alive.”

- Maya Angelou

Thumbs up for a great family and a great future!

David is an important member of our family. I often forget how much I worried as David was growing up, now when I look at photos from those childhood years I realise I should have enjoyed those times a lot more and worried a lot less. David is quite a character and he fits right into our family. So please, learn to relax and enjoy the childhood years.  - Peter Elliot (DSRF trustee)

Group Hug! David with his sister and his nephew.
Words of Wisdom

An interview with Astra Milberg

National Post writer Allen Abel recently spoke to 12 people who have had remarkable experiences. Today, in the final part of the series, we meet Astra Milberg, 28, of Toronto, Canada. Astra is involved in a number of community organizations and is the recipient of the Lieutenant-Governor of Ontario’s Volunteer Action Award.

Here is what Astra has to say about her life (Astra has Down’s syndrome)

I hear people say, “I’d rather be dead than like that.” Whoever said that, he has his own problems. What I have, I can’t get rid of it. I guess I’m not the only person with it. Me, I’m proud. Look at the things I am doing. Others with Down syndrome, they are still hidden away. They don’t want to talk about “the label.” But I figure I’m pretty much here to stay. As long as I’m around, it’s not going to go away.

I know it’s not curable. I wish it was. I actually heard, on one of the tapes I have, a man mentioning a pill you could take to make this go away. It would be nice if there was a pill like that, to become like some other people. If I didn’t have Down syndrome, it would be different; I would know what reality is. To me, a dream is just a dream. When I dream, I go after cloud nine, but I’m just daydreaming and it’s not reality. I wake up from all my dreams. Most of those dreams don’t come true.

My moods are up and down. One moment, I’m happy; the next moment, I’m upset. Sometimes the sun comes out, and sometimes it hides behind a cloud. That’s how I am. More or less, I go with the moods of the weather. What makes me happy is being a friend to a person. I know a girl – everybody else wasn’t nice to her because she was a drug addict and an alcoholic. But a person like that needs friends. I don’t know how much she remembers of our friendship, but I remember it, and it makes me happy.

I don’t have any physical pain. I know I am short – that I do admit! But being short is actually nice – I can get myself out of trouble without being seen! Sometimes, it is hard for me to concentrate. When it comes to life and reality and the way to live, sometimes I get confused. But if I get in trouble, I know how to get help. I wouldn’t say I get dizzy, but sometimes I get confused about life and its difficulties. If I have a home I can get back to, I can do things outside.

Sometimes I get lost, and sometimes I can orient myself and not get lost. When I was younger, I used to get lost a lot and the police would bring me back. At least I know that they are friends – it’s not like they put me in handcuffs.

They are very friendly, even to people with disabilities. I could see myself working in a police station. I’m not afraid of going on the subway. I’m just afraid I’ll get pushed in the pit! And I’m not afraid of noise, unless it’s a gunshot! Thunder and lightning, I’m not afraid of – I like them.

I am pretty well literate. Writing, I do every night in my diary. Everybody says I should become a novelist, the way I write. But what I write is just between me and my Mom. I was born in Toronto. I’m a legal Canadian with the right to vote. I like that. Most people with disabilities don’t vote. I don’t exercise very much. I used to exercise, a long time ago. I did run when I was a child. Now, I walk. Walk and talk – there you go! I don’t watch a lot of TV. I watch the rough and tough ones: Xena, Warrior Princess and Walker, Texas Ranger. (Don’t put that down!)

When I look at other people with Down syndrome, I see some people with speech impairment. Some have fears that are in their heads but the fears are not reality. I pick up on that. It’s hard to make something positive out of so many negatives. Sometimes people say that having Down syndrome is cool. How cool, I don’t know. Some people say I have special talents. Sometimes, they are surprised by what I actually know. I do have a sense of humour – not everyone has that.

Looking beyond people with disabilities, and watching those people do things, I think, “I can do some of the stuff that they do.” Most people have some kind of disability. They get hurt in many ways, too. But it’s not the same as having Down syndrome. Everybody says that I need a soul-mate, but getting a boyfriend is hard. I had a few recent ones who said that they loved, but they actually don’t. Now, I have new ones, but I wonder, will they be like the ones before? When you have a recent breakup that happens, a person loses the will to love.

Some people know about love, they know that they will love again. But, it’s hard. I can get guys’ attention, but not the ones I want. I get lonely sometimes. I know that people say that you’re never really alone – that’s God they’re talking about. I go to church, we’re Christian.

I pray for the family I used to have when they were a larger group – my grandmother, my aunt. I pray for myself sometimes. For myself, I pray for peace, love. Once, when I was working at the Bob Rumball camp, I fell asleep to the sounds the deaf were making, and it sounded like music. That night, I saw the light of Heaven. It was just a bright light – no face, nothing – just peace. I wrote that down in my diary so I can keep the feeling with me.

Some people say that babies with Down syndrome have beautiful eyes. Not all. But some of us do.

Astra Milberg

Copyright: The material contained in this file is made available courtesy contributors and editors of Pro-Life E-News. Copying of this material is free for non-commercial educational and research use. Unless explicitly stated, copyright of this material is owned by the author and/or sponsoring organization, and/or newswire services.
This booklet is distributed FREE where there is a family member with Down’s Syndrome or a pre-term diagnosis of Trisomy 21 from a screening test.

Tell us who you are and what you need in a short letter - and send us a Stamped - Self addressed - Large envelope.

Our Members donations cover this printing cost - Please become a Friend of the DSRF-UK and support this important work - Registered Charity 1058548

The Down’s Syndrome Research Foundation, Wycombe Road, Saunderton Estate, Bucks, HP14 4BF
(Note: Medical Professionals and Medical students can get a free copy - For Bulk orders we will need an approved Purchase order - books must be distributed free)

www.dsrf-uk.org

Copyright 2011 - All rights are reserved - Contact the above address for permissions.