When your unborn baby has a problem

How to manage the weeks ahead

A BOOK FOR FAMILIES

The Centre for Genetics Education
March 2006
Acknowledgments

SAFDA was formed by a network of professionals who offered support and information for people who experienced the diagnosis of a problem in their unborn child.

SAFDA was successful for many years and has fulfilled its aim of providing support and raising awareness of needs after the diagnosis of a fetal abnormality. Due to an increased work load and the restructuring of services, SAFDA no longer exists. This booklet however will remain as a testament to the invaluable work many people put into setting up SAFDA.

The Association of Genetic Support of Australasia (AGSA) whilst not trying to emulate SAFDA, has received funding to follow on SAFDA’s work by providing counselling and, where possible, contact with other individuals in like circumstances. A qualified Genetic Counsellor who is also a Registered Psychologist has been employed to counsel individuals on a needs basis. For referral please phone AGSA to make an appointment time. There is no charge to the individual for face to face counselling.
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ABOUT THIS BOOKLET

This booklet has been written for parents who have received a diagnosis of a problem in their unborn baby, and who are deciding to continue their pregnancy in the light of that knowledge.

This is a time of mixed feelings: devastation, sadness and uncertainty. It can also be a time to prepare for the future. It is not possible in this short booklet to address every situation that parents encounter. However, the main themes and issues that you may meet in your pregnancy and in the early weeks and months of your baby’s life have been addressed.

The resource section will help point you in the direction of information and organisations that can assist as your pregnancy progresses.

Please note in this publication the word “baby” has been used throughout, irrespective of the stage of pregnancy. “You” may refer to one parent, both parents or other people involved with your situation. “He” and “she” have been used randomly throughout the text in reference to the gender of your child. The comments made are not intended to be gender specific.
For most parents, the news that an abnormality has been identified in their unborn baby is completely unexpected. A problem or abnormality identified in the developing baby generally comes as a shock.

The baby’s problems may have been seen through an ultrasound examination offered as a routine screening test. Perhaps they were identified as a result of screening with the Maternal Serum or Nuchal Translucency Tests. The diagnosis may have been made by prenatal diagnostic procedures such as CVS (chorionic villus sampling) in the first trimester of pregnancy or by amniocentesis in the second trimester. Whichever way the diagnosis is made, most people are quite unprepared for the reality.

Some couples who considered CVS or amniocentesis, have had prenatal diagnosis counselling. During this process, they may have had the opportunity to discuss their feelings and concerns about the possibility of a test result revealing a problem in the developing baby. Other couples have thought of this possibility because they have a family history or a previous child with a particular condition for which the current pregnancy is at risk. You may have a condition yourself which has now been detected in your baby.

In the light of the technologies available to monitor pregnancy, more and more abnormalities are also being identified through “routine” examinations such as ultrasound. Often the parents of babies identified in this way, have never given consideration to the possibility that such a routine test would find something wrong with their unborn baby.

You may have received the news by telephone, or in person from your doctor, a genetic counsellor, obstetrician or ultrasonographer. Quite often the person who tells you such painful and personal news is a stranger to you and sometimes the news may not have been given in a gentle or thoughtful manner. People sometimes relive the experience of hearing the results for some considerable time. Many parents describe a sense of unreality after hearing the diagnosis.
MAKING YOUR DECISION

Making the decision to continue your pregnancy can be one of the most difficult and painful decisions you will ever have to make. There are many factors which affect decision making at this most difficult of times; family history, belief systems and values, late diagnosis, previous life experiences or support networks.

Some people make the decision to continue the pregnancy because they have a strong religious or spiritual belief about the sanctity of life. Support from friends, family, doctors or your church community may have given you the strength you needed to continue and feel a sense of hope about the birth of your baby.

“We couldn’t justify finishing something we already felt close to”

“I firmly believe that this is our son no matter what, and to end his life doesn’t solve the problem but creates a new one”

“I had a sense that she wanted to live. I truly felt like love would conquer all”

For many people, the later the diagnosis is made in the pregnancy, the more difficult it becomes not to continue. For some, a diagnosis in the baby has not been definitely established and therefore some optimism remains about the baby’s outcome. This helps to make the decision to continue.

If your doctor has told you that your baby’s outcome will probably be a good one or that there may be some treatment available after birth, this could have helped you to decide.

Whatever the basis of your decision, an unknown future for you, your child and other immediate family members can lead to intense feelings of anxiety and stress. Not knowing the degree of severity of the condition is often a further source of difficulty.
• How will I cope with a disabled child?
• What will my child look like?
• How severe will her problems be?
• What help will be available if we need it?
• Will he be accepted by other people?
• What kind of life will she have as a teenager, or as an adult?

“Our main worries were keeping our family as normal as possible, especially for our other two sons”

“I was concerned with how my husband, a very active man, would cope with a disabled child”

“I didn’t want to live life with a child who had a disability”

You may not have met with much encouragement to continue your pregnancy. Sometimes doctors, radiologists or your family can be critical of this decision and may try to discourage you from giving birth to a baby with a medical problem. To make a decision in the face of opposition is a very difficult and courageous thing to do.

“Some responses were positive and constructive. The negative annoying comments like ‘God chose you’ I learned to ignore. People were often embarrassed as they don’t quite know what to say. Learning not to take comments to heart helped”
Like many others, you may be feeling numb, confused or alone. This numbness and sense of unreality is part of the shock reaction. Some people have physical reactions as well, such as nausea, shortness of breath, rapid heartbeat or feeling faint. Often parents cannot believe what they have heard and will want frequent reassurance that the diagnosis is correct. It is perfectly acceptable for you to question the accuracy of the information and even to seek a second opinion about the diagnosis from another medical expert.

Once the feeling of numbness subsides, parents describe feeling intense anger and sadness about knowing that their baby has a serious problem and about the prospects that lie ahead. It is normal to ask “why me?” even though there may be no answer to this question. Finding out that your unborn baby has a problem is one of life’s most unjust events and it is very difficult to accept.

The sadness you experience can be overwhelming and takes many forms. Sleeplessness, loss of appetite, apathy and depression are some of the possible reactions you could have. You may shed many tears, for months and possibly even years, down the road.

“I cried a lot. By the time my child was born I had gone through many of the levels of grief”

It is not unusual for the parents, particularly the mother, to have feelings of guilt. Regardless of the cause of the baby’s problems, it is common to wonder if you could have possibly contributed to the abnormality; or if anything could have been done to prevent it from happening. Sometimes a parent feels guilty because they have had ambivalent feelings about the pregnancy.
Whatever the cause of your unborn baby’s problem, it is unlikely that there was anything that you or your partner did or did not do that made it happen. Many of the problems found in a developing baby are “chance” events. Even if the problem is hereditary, no one can control which genes a baby inherits from its parents. It may be helpful to remind yourself that neither you, nor your partner is to blame for your baby’s problem.

If your doctor, family or friends have not supported your decision to continue your pregnancy, you may be feeling angry, hurt and alone. Sometimes peoples’ well intentioned comments can be very wounding or sound offensive. They may have difficulty in understanding how important this baby is to you and your partner.

“It does not matter what other people think; you have to be happy with the baby yourself”
WHAT IS IMPORTANT FOR YOU AT THIS TIME?

At the time you receive the diagnosis, you may be up to half way through your pregnancy. The 20 weeks or so that remain can be some of the most difficult weeks of your life. Some parents want to start planning and organising straight away. Others may feel they don’t want to be flooded with information and worst-case scenarios, but do want to plan for the birth and have contact with the staff who will be caring for them and their baby in hospital.

It is important to allow yourself time to experience and accept your emotions both now and in the days, weeks and months ahead. The impact of a diagnosis of an abnormality in your unborn baby may be felt by both parents in different ways, so it is important to share your thoughts and feelings with each other.

Great demands are placed on all your relationships at this time. You may find that your partner, like you, is overwhelmed with feelings. You may want to involve other family members and friends as supports and sounding-boards for you both. If you do not have a partner, you could consider seeking support from someone close to you.

You will find that you have to make your way through a complex medical system. You will have a lot of questions and you do have a right to have those questions answered. Your obstetrician may not have all the information you need, and you can ask to be referred to a specialist paediatrician or other source of information.
You may want to seek a second opinion, or seek out a specialist unit, or consult the Internet for further information (although you should check with your doctor for accuracy if you do this). You can ask your doctor for written material or videos that will help you gain a picture of what the disability actually means.

“We wanted more in-depth information about each individual disability and its upside, not the downside; the positives, not negatives; the joy, not the misery”

It may also be helpful to ask to be put in touch with a parent support group if there is an appropriate one for your child’s problem. If there is no support group you could ask to be put in touch with someone else whose child has the same diagnosis. This may help reduce your anxiety about the future and enable you to start to prepare for your baby’s arrival in a positive way.
YOUR HEALTH CARE TEAM

This is probably an appropriate time to focus briefly on the medical team who will be helping to care for your baby.

If your baby has a condition which will need ongoing medical attention, you may find that you are having to relate on a daily basis to a wide range of health professionals. For this reason, it is important that you are comfortable and confident in the hospital and the relationships you have with the health professionals caring for you.

“It’s easy to get flooded with information, you’re meeting a cast of thousands”

Here are some suggestions to help you make sure you understand your baby’s condition and possible treatment. They may also help you to prepare for his birth and to regain some control of your situation.

• You may find it helpful to ask your doctor for a “care map” or a written version of the suggested treatment plan for your baby in the first few weeks.

• You may choose to buy a folder with a flap to keep everything in – diagrams, leaflets, calling cards etc – and to have a notebook in which you can record the events of each day and any questions you want to clarify.

• Ask if the medical team/s have a list of their key personnel, including allied health professionals. Allied health professionals include people such as social workers, physiotherapists and occupational therapists.

• Some medical teams may designate someone who can act as a consistent source of information for you. More frequently, you may find that you see a confusing array of interns, registrars and technicians.

• You can ask for one person to be nominated with whom you and your partner can have a regular meeting – once or twice weekly if necessary. This provides a built-in opportunity to clarify your concerns and update plans. This person may be able to act as a co-ordinator for you, particularly if there are a lot of medical personnel involved in your child’s care. Much of the stress involved in managing your medical appointments can be relieved.
“We wanted a case manager to guide and co-ordinate”

You can ask that your specialists meet and talk to you as a couple. Some fathers may not feel as comfortable and familiar in the hospital environment as their partners. It is important that health professionals avoid the tendency to talk primarily to the baby’s mother and ignore the father.

“I needed the facts, given honestly. Some other parents may not question as much”

“It would be great if (our doctors) could have improved information that could be disseminated to parents at this time”

“I would like to have had a register set up so that the obstetrician could direct parents to the specialists who know about the specific condition”

To sum up, in dealing with your health care team, you are entitled to ask for:

• honesty
• up-to-date and accurate information (as far as this can be given for your baby’s condition)
• support
• organisation and structure for your baby’s admission

“We wanted a wise person who can talk/listen – someone to hold our hand and go through the issues”
You have had to adjust to the shock of the diagnosis, to unfamiliar medical terms and to meeting a host of medical professionals. It is often not easy to know how to explain your unborn baby’s problem to others, when you barely understand it yourself. The needs and feelings of your other children can also be hard to deal with.

However, it certainly helps if people around you know your baby has a problem, and that he may need transfer to specialist care, or surgery, after birth. They can then be more sensitive to your needs after the birth. You can let them know that you would still like them to recognise how much your baby’s arrival means to you. You may wish to nominate one or two key people as information sources for the early days. It can be exhausting receiving phone calls and explaining to others when you have just come out of hospital.

The responses you receive from friends and other family members may be disappointing or hurtful.

Some people may not understand why you have chosen to continue a pregnancy when you know there is a diagnosed problem. They may feel that you somehow asked for all the trauma and difficulties when you made the decision you did. They may not be able to allow you your possibly mixed feelings of sadness and frustration.

“Well, you asked for this. You knew it would be like this and yet you went ahead”

Some parents have found that they have to keep their distance from certain family members, to protect themselves from negative reactions, at least at first.

“It was lucky I lived 300 km away!”

It can be helpful to “rehearse” some standard answers to people’s questions. It is quite OK to tell yourself that on days when you’re feeling strong, it is your choice to go into details and explanations but on days when you are feeling more vulnerable, it is your right to say so.

“I just don’t get involved with people I know will be negative”
PREPARING FOR THE BIRTH

Often you are preparing for a very uncertain future. Your medical team may not be able to provide you with specific and detailed information about your baby’s condition.

This section focuses on the plans you can make during what remains of the pregnancy. Perhaps your baby is not expected to survive the birth or newborn period or is expected to have ongoing problems and a need for medical care.

We hope that the following suggestions may be helpful.

If your baby is not expected to survive the birth or newborn period

The remaining months of the pregnancy can be a very precious time, when you can make the most of the connection with your baby:

- walking by the beach or in a special place;
- communicating your thoughts and perhaps keeping a journal;
- creating positive and very real mementos of your pregnancy such as photographs, copies of ultrasounds and special occasions.

All these memories help to sustain you after the death of your baby.

You may find it helpful to plan the birth, to think about who will be there – your partner, other children, parents etc. Some parents have asked a friend to take a video of the very early minutes or hours of their baby’s life. You can take music, your favourite quilt, flowers – anything you like, into the hospital delivery room. One mother bought an outfit for her baby and because she knew her daughter had anencephaly (absence of the skull) she chose a bonnet that would cover the head. She did not want her other children to be alarmed by their first sight of their sister.

“Although no-one wants their child to die, it was something as a family we talked about. My children, although only 2, 4 and 6 years old, were to be at the birth in case this occurred so they could see their sister”
Many parents whose babies have been diagnosed with physical problems on ultrasound, have fears about how their baby might look when it is born. In most cases these fears are always greater than the reality.

Some parents have chosen to meet the hospital social worker and other staff before the birth, and to seek information about funerals and other practicalities. This means you can make preliminary decisions in a calmer time, choose a funeral company you feel comfortable with, and discuss your plans with the hospital staff.

“We discussed a prepaid funeral and made decisions about what we would and would not allow”

Usually, you can have your baby in your room with you after the birth for as long as you wish, or in the Newborn Intensive Care Unit or a nursery area if you need to rest.
Discuss with your doctor or the nursing staff, ways in which you can spend some time alone with your baby, perhaps outside the hospital setting if possible. This may be a visit to a quiet area such as a park or you may be able to take your child home with you. When children have serious problems which can be managed just as well at home as in hospital, this may be an option you can consider. In some cases, parents may need to be shown some things that they will need to do to make the baby more comfortable, such as providing the baby with extra oxygen.

“We wanted our baby to die at home... and we wanted to handle as much at home as possible”

You can bathe, dress and hold your baby for as long as you wish. Most hospitals have chaplains or pastoral care workers and you may wish to hold a simple blessing or naming ceremony for your baby. If you have particular cultural or religious practices which are important for you, discuss these with the staff in advance, or at the time.

You will find great support and information from the parents in SIDS and KIDS NSW – see resource section for contact details.

If your baby dies at birth, in order to help you understand why the problem developed, your doctor may recommend that you consider a post-mortem for your baby. The doctor performing the post-mortem is usually a specialist pathologist, and will undertake a thorough examination of your baby. You can consent to a full post-mortem, or a limited post-mortem in which only part of the examination and some of the tests are undertaken. Parents may see and hold their baby after a full or limited post-mortem.
If your baby is expected to have ongoing problems and a need for medical care

As we suggested previously, other parents have emphasised how helpful it is to meet the medical team beforehand so that you are familiar with them and with possible events after your baby’s birth.

The birth itself may not be as easy or straightforward as you would have wished. You and your baby might need to be transferred to a specialist centre antenatally, far from home and familiar supports. You may have a planned caesarean, so the paediatric team can be available and standing by to offer care for your baby if it is needed.

Some people have asked for a single room in hospital, so that their privacy is protected after the birth.

It is possible that your baby may need surgery after birth. Will your baby have to be transferred to a specialist children’s hospital? If so, it is helpful to find out what facilities they have for parents to live in, and for your transfer postnatally to the nearest maternity unit if there is a distance involved.

You can discuss with your obstetrician and specialist the sort of contact you can have with your baby after birth. It may not be necessary for your baby to be transferred immediately; you may be able to have an hour or two to hold your baby and spend time as a family before the difficult separation.

Having someone to video this early time, and then video your baby in the paediatric ward, is helpful. You can see for yourself how your baby is, and you have a record of those days you may have been separated so that you can “fill in the gaps” psychologically.

“If parents don’t own a video – the hospital should take one!
It was fantastic”
If you are planning to breastfeed, it’s helpful to gather information about breast pumps beforehand, and to know how your milk will reach the paediatric ward for use or for storage if your baby is not yet ready to feed. Will you have access to a lactation consultant at your hospital? The Nursing Mothers Association of Australia have experts who may be able to help you if you have any problems.

Many hospitals run courses for pregnant women and their partners during pregnancy which help prepare you for birth and breast-feeding.

Some women find that having a photograph of their baby to look at while they are expressing, helps increase their milk supply. One mother suggested a one-way mirror on the wall of the NICU expressing room “so that you can see a baby, even if it’s not yours!”

You may be facing a long period of hospitalisation for your baby. It is important to try to keep a balance and look after yourself. It’s likely that your will encounter a multitude of feelings:

- **anger and disappointment** that you could not have the kind of non-interventionist birth you wished
- **sadness** at the loss of a perfect baby whom you could have with you and care for without complex medical care
- **exhaustion** after the months of preparation
- **resentment** of other women in your ward whose concerns seem very minor by comparison with yours.

Investigate the possibility of sleeping at the hospital near to your baby. However, if you are in for a long haul, you may find it is helpful for your sanity and sense of normality to spend some time at home or to go home some nights rather than live in beside your baby. Because your baby was born with a disability, it is easy to feel that you “should” be there 24 hours a day to stick by the bedside.

“It’s hard to argue against that feeling of guilt”
If you are far from home, try to ensure you have people to help share this time – partner, family and friends who can stay even for a few days.

“Don’t try to be a hero”

It is perfectly normal to feel exhausted during a long hospitalisation; many hospitals run parent groups or coffee mornings which can be very sustaining and help lessen your sense of isolation. They may also offer massage or relaxation programs. If you are in a smaller hospital, you may consider getting someone in to perform this.

Most paediatric wards have a social worker attached, whose role it is to help you voice your feelings in a safe environment and ease your contact with the medical team. Most hospitals also have chaplains available, and a chapel or quiet room where you can sit in privacy. One mother said the beautiful stained glass colours and images comforted her during weeks in a hospital far from home.
GOING HOME

Your feelings may emerge only slowly, as you recover from the birth and the actuality of your baby's condition. You could feel sad and tearful and be deeply disappointed that the problem has been confirmed – no miracle has taken place between the diagnosis and the birth. You may be anxious for the future, about the commitment this will demand from you as a family and about the intervention and care your child will need. It is possible you are feeling cheated of the kind of pregnancy and parenthood that you had been hoping for.

You may find at first that you focus solely on the baby and his or her needs, and almost go into automatic mode. It may be hard to feel much at first, or to make decisions, no matter how well you have prepared. The reality of the birth in itself can be a shock just as the diagnosis is.

“The bottom line is, there’s really nothing to prepare you”

Before you leave hospital, it is a good idea to ask what sort of follow-up will be provided. Will you be linked to a local or specialist disability service? If you are feeling isolated and want someone to talk to about how things are going at home, it is always possible to renew contact with the hospital social worker or seek other counselling support.

Going home with your baby can seem a daunting step, especially when you have been in a ward with nurses and other staff around to help you. Some hospitals may have a home visiting or parent support team who can ease your first few weeks at home.

If there is a support group for your baby's condition, it may be helpful to make contact with them. The families in the group have already negotiated a pathway through their child's medical care, and may have some invaluable strategies and support.
Deciding when, or if, to make contact is a very individual decision. Possibly you may not be ready to do this for several months. Be guided by your own instincts.

You may find it hard at first to love and accept your baby. You may be filled with feelings of jealousy towards other able-bodied children, or women with a “healthy” newborn.

Nearly all parents eventually feel very strongly bonded to their child and express freely the pleasure their children have brought to their lives and to the lives of those around them.

“Because I had grieved for 10 weeks and had also talked constantly to her when she was born, my maternal instincts were overwhelming. I felt I knew this little girl growing inside me with all the hurdles we all had to face together. I couldn’t wait to breast feed her, to love and support her”

“We treated our baby like a patient for the first 6 months. At 6 months it suddenly hit me and I realised what a beautiful son we had”
IN CONCLUSION

There are many excellent sources of help and support for parents in the long-term after the birth of a baby with a disability. Our aim has been to offer suggestions that may help you through the pregnancy and early weeks.

There may be no short cut through the ongoing grief you experience as the parent of a child with a disability. You are faced with the need for ongoing care and involvement with medical and other professionals. As a parent you enjoy and worry simultaneously. We would not wish to minimise the sense of hurt and sadness, nor the pleasure and pride you can have in your child. But we do believe that it is possible to lessen the sense of chaos and fragmentation that you feel at the time of the birth, and post-natally, to some extent. We hope that the experiences and reflections of other parents have helped you too, to consider how you would wish to approach this demanding time.

“By the time she was born I believe I was ready to face any diagnosis”

“We have not become a disabled family, but rather a family with a child who has a few disabilities”

“There has been a lot of growth both in ourselves, and in closeness to each other”
AGSA
The Association of Genetic Support of Australasia
66 Albion Street, Surry Hills NSW 2010
Tel: (02) 9211 1462
Fax: (02) 9211 8077
Email: agsa@ozemail.com.au
www.agsa-geneticsupport.org.au
An umbrella organisation with a client database representing over 500 genetic conditions and a rare chromosomal abnormalities contact register.

AWCH
Australian Association for the Welfare of Child Health Inc
PO Box 113
Westmead NSW 2145
Tel: (02) 9631 9208
Fax: (02) 9631 9390
Tollfree: 1800 244 396
Email: awch@awch.com.au
A voluntary, community organisation with an extensive library and database of resource materials and information about support groups.

AMBA
Australian Multiple Birth Association
PO Box
Coogee NSW 2034
Tel: (02) 9502 2429
Email: secretary@amba.org.au
AMBA has established a special needs Register to offer support and resources to families where one “multiple” has special needs.

Australian Breastfeeding Association
4 McMullen Avenue
Castle Hill NSW 2154
Tel: (02) 8853 4900
Fax: (02) 8850 2199
Email: nswoffice@breastfeeding.asn.au

SIDS and KIDS NSW
Bldg 301, Rozelle Hospital Campus
Balmain Road
Rozelle NSW 2039
Tel: (02) 9818 8400
Fax: (02) 9818 4555
A support & resource for bereaved parents who lose a baby at any stage during pregnancy or in the newborn period.

The Centre for Genetics Education
PO Box 317
St Leonards NSW 1590
Tel: (02) 9926 7324
Fax: (02) 9906 7529
Email: genetics@med.usyd.edu.au
www.genetics.com.au
Information about genetic conditions and details of genetic support groups.

The Donor Conception Support Group of Australia Inc
PO Box 53
Georges Hall NSW 2198
Tel: (02) 9793 9335
Email: dcsg@optushome.com.au
www.members.optushome.com.au
DEPARTMENT OF COMMUNITY SERVICES

The telephone number is under Community Services in your telephone directory. Resources include early intervention and developmental disability teams with a range of specialist expertise.

SUPPORT GROUPS

AGSA, The Centre for Genetics Education and AWCH are excellent sources of information about different conditions and support groups, in Australia, overseas, or on the Internet. Some of the major support groups for more common conditions are:

**Cystic Fibrosis New South Wales**
51 Wicks Road
North Ryde NSW 2113
Tel: (02) 9878 2075
Email: general@cysticfibrosisnsw.org.au

**Down Syndrom Association**
31 O’Connell Street
Parramatta NSW 2150
Tel: (02) 9683 4333
Email: admin@dsansw.org.au

**Chromosome Support Group**
c/o AGSA
66 Albion Street
Surry Hills NSW 2010
Tel: (02) 9211 1462
Email: agsa@ozemail.com.au

**Spina Bifida Group**
PO Box 4055
Parramatta NSW 2151
Tel: (02) 9890 0100

Centres for genetic counselling, prenatal diagnosis and counselling throughout NSW and other Australian states and territories are listed in the following pages.
CLINICAL GENETICS SERVICES –
GENERAL GENETIC COUNSELLING

Camperdown
Department of Molecular and Clinical Genetics
Royal Prince Alfred Hospital
Building 65, Level 6
Missenden Road
Camperdown NSW 2050
Tel: (02) 9515 5080
Fax: (02) 9515 7595

Liverpool
Department of Clinical Genetics
Locked Bag 7103
Liverpool BC NSW 1871
Tel: (02) 9828 4665
Fax: (02) 9828 4650

Nepean
Clinical Genetics Department
Nepean Hospital
PO Box 63
Penrith NSW 2750
Tel: (02) 4734 3362
Fax: (02) 4734 2567

Newcastle
Hunter Genetics
Cnr Turton and Tinonee Roads
Waratah NSW 2298
Tel: (02) 4985 3100
Fax: (02) 4985 3105

Randwick
Department of Medical Genetics
Sydney Children’s Hospital
High Street, Randwick NSW 2031
Tel: (02) 9382 1704
Fax: (02) 9382 1711

Royal Hospital for Women
Centre for Fetal Medicine
Barker Street
Randwick NSW 2031
Tel: (02) 9382 6098
Fax: (02) 9382 6706

St George
Women’s and Children’s Health
St George Hospital
Gray Street
Kogarah NSW 2217
Tel: (02) 9350 3635
Fax: (02) 9350 3901

St Leonards
Genetic Counselling
Royal North Shore Hospital
Clinic 10, Main Block
St Leonards NSW 2065
Tel: (02) 9926 6478
Fax: (02) 9926 7880

Westmead
Department of Clinical Genetics
The Children’s Hospital Westmead
Hawkesbury Road
Westmead NSW 2145
Tel: (02) 9845 3273
Fax: (02) 9845 3204
Bathurst
Bathurst Community Health Centre
PO Box 1479
Bathurst NSW 2795
Tel: (02) 6339 5677
Fax: (02) 6339 5655

Broken Hill
Broken Hill Primary Health Service
PO Box 457
Broken Hill NSW 2880
Tel: (08) 8080 1554
Fax: (08) 8080 1611

Canberra
The Canberra Hospital
PO Box 11
Woden ACT 2605
Tel: (02) 6244 4042
Fax: (02) 6282 2844

Coffs Harbour
Coffs Harbour Health Campus
Locked Bag 812
Coffs Harbour NSW 2450
Tel: (02) 6656 7000
Fax: (02) 6656 7687

Gosford
Central Coast Health
PO Box 361
Gosford NSW 2250
Tel: (02) 4328 7994
Fax: (02) 4328 7925

Goulburn
Child Development Unit
Locked Bag 15
Goulburn NSW 2580
Tel: (02) 4827 3951
Fax: (02) 4827 3958

Mudgee
Mudgee Community Health Centre
PO Box 29
Mudgee NSW 2850
Tel: (02) 6378 6236
Fax: (02) 6372 7341

Muswellbrook
Community Health Centre
PO Box 120
Muswellbrook NSW 2332
Tel: (02) 6542 2050
Fax: (02) 6542 2001

North Coast
Child and Family Health centre
Lismore Base Hospital
37 Oliver Avenue
Goonellabah NSW 2480
Tel: (02) 6625 0111
Fax: (02) 6625 0102

Port Macquarie
Port Macquarie Community Health Centre
Morton Street
Port Macquarie NSW 2444
Tel: (02) 6588 2882
Fax: (02) 6588 2800
OUTREACH SERVICES ARE AVAILABLE AT:

Tamworth
Community Health Centre
PO Box 83
Tamworth NSW 2340
Tel: (02) 67662555
Fax: (02) 6766 3967

Taree
Mid North Coast Area Health
PO Box 35
Taree NSW 2430
Tel: (02) 6592 9703
Fax: (02) 6592 9607

Wagga Wagga
C/o Harvey House
Wagga Wagga Base Hospital
PO Box 159
Wagga Wagga NSW 2650
Tel: (02) 6938 6393
Fax: (02) 6921 5632

Wollongong
Wollongong Hospital
Private Mail Bag 8808
South Coast Mail Centre NSW 2521
Tel: (02) 4253 4267
Fax: (02) 4253 4257

Services are available in most stages and territories.
The contact numbers are listed below:

ACT
Tel: (02) 6244 4042
Fax: (02) 6244 3422

Northern Territory
C/o South Australia
Tel: (08) 8204 7375
Fax: (08) 8204 6088

Queensland
Tel: (07) 3636 1686
Fax: (07) 3636 987

South Australia
Tel: (08) 8204 7375
Fax: (08) 8204 6088

Tasmania
Tel: (03) 6222 8296
Fax: (03) 6222 7961

Victoria
Tel: (03) 8341 6201
Fax: (03) 8341 6390

Western Australia
Tel: (09) 9340 1525
Fax: (08) 9340 1678
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