



# THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA INC. (AGSA)

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NEWSLETTER

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## MISSION STATEMENT

To facilitate support for those affected directly or indirectly by genetic conditions throughout Australasia.

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## EDITORIAL

We hope you had an enjoyable Easter break!

AGSA made its submission to the Australian Law Reform Commission and Australian Health Ethics Committee regarding the Issues Paper – Protecting Human Genetic Information. We look forward to the outcome of the inquiry.

Genetic Awareness Week is fast approaching and is planned for the week of June etc. This will be held at the Powerhouse Museum as in other years and we expect to have topics/speakers?

Seminars planned for the year...

We will be sending out membership renewal forms in the next newsletter – in June. We appreciate your continuing support for the vital work that AGSA does.

Best Wishes

Dianne Petrie & Halimah Simpson





## CONTACT CORNER

AGSA will publish requests for contacts and letters from people searching for families with similar experiences, from those seeking or contributing specific information as well as other resource information.

Anyone who wishes to reply to a request or a letter should write direct to the individual or group concerned where an address is provided. The AGSA office may be contacted for the information to be passed on in the case of anonymous requests. Privacy and anonymity will be ensured if requested.

While AGSA aims to facilitate contacts between families it is unable to assess the suitability of these in individual cases.

It should be remembered that a shared genetic condition does not mean an equally shared value system between families. Different degrees of acceptance and different mechanisms for coping will be encountered and a non-judgmental approach is recommended in establishing contact.

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### DELETION ON 11<sup>TH</sup> CHROMOSOME

The mother of a 21 month year old girl would like contact with other families for information sharing and support. Contact AGSA for details.

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### SPONDYLO EPIPHYSEAL DYSPLASIA CONGENITA

A gentleman with this condition seeks contact with others. Contact AGSA for details.

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### INCONTINENTIA PIGMENTI – STAGE 2

The mother of a 7 year old girl would like contact with others experiencing this condition. Contact AGSA for details.

### PARTIAL DISOMY ON THE X CHROMOSOME

The family of a 5 year old boy would like contact with others with experience of this condition. Contact AGSA for details.

### ALAGILLE SYNDROME

The mother of a 1 year old baby girl would like contact with others with experience of this syndrome. Contact AGSA for details.

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## SUPPORT GROUP NEWS

**Chronic Illness Alliance** The Council of Social Service of NSW (NCOSS), has taken on the chair of Chronic Illness Alliance (CIA), a group of chronic illness groups such as Motor Neurone Disease

Association, Cystic Fibrosis Foundation, and Hepatitis C Council. NCOSS is working with the group to develop an agenda for advocacy and links with other sector organizations.

### Domestic Violence Against Women with Disabilities Project

Macarthur Area Assistance Scheme and the Benevolent Society have funded a four-year project to improve service and community responses to women with disabilities who are surviving domestic violence in the Macarthur region. For further information call Janine or Maggie on (02) 4627 2792 (voice and TTY).

### Workplace Bullying: Practical Solutions

Date: May 23, 2002 Venue: RSL Club, Joseph Street, Lidcombe, NSW.

Hear presenters from industrial medical, legal and personal perspectives discuss experiences or workplace bullying including ideas to help overcome this increasing occupational hazard. If you have ideas to share, this is an opportunity for workers to develop practical solutions. Enquiries: Workers Health Centre, (02) 9749 7666

### FREE COMPUTERS & NETWORKS!



**Computerbank Australia** provides free computers and installs networks for charities, schools and non-profit organizations. Computerbank are being offered more computers than they can either store or donate. Plus they have many engineers who are willing to install the computers as either free-standing PCs or networks. Contact Richard Hayes at [help@cbnsw.org.au](mailto:help@cbnsw.org.au) or Tel: 0414 618 425 to apply for computers. Visit the website: [www.computerbank.org.au](http://www.computerbank.org.au) to find out where the branch is in your in state.

**Lymphoedema Information Day** at Westmead Hospital on Saturday April 6. Enquiries about Lymphodema Support Group or Information Day: contact Barbara Smith on (02) 9402 5625.

## PROFILE

### A – Z GENETIC CONDITIONS

*It is the intention of AGSA to profile, in each issue, a particular Support Group/Disorder, thus increasing awareness within our membership of the range of genetic conditions. Also it hopes that where overlaps occur in conditions, support Groups may liaise with each other and thus gain a broader understanding of facilities, aids, etc. that may be of value to your individual membership.*

*Please ensure that all support group information is recent and reliable. It is of paramount importance that you let us know your group is "Alive and Well" and happy to take referrals.*

## LUPUS: A WOLF IN SHEEP'S CLOTHING

Systemic Lupus Erythematosus (commonly called Lupus or SLE) is a chronic auto-immune disease in which the antibodies which fight invading bacteria and viruses, attack and accumulate in the bodies own tissues, causing inflammation, damage and pain.

Nine out of ten sufferers are women and 90 percent of these develop the condition during their reproductive years, although men and other age groups can also be affected. If you have Lupus, the chance that you will have another family member with Lupus is 5-10%; for identical twins, if one twin has Lupus then the chance that the other one will get lupus is 23-57%.

### Symptoms

Lupus is a complex multi system inflammatory disorder in which a variety of body organs may be affected. Externally, the sufferer may give the impression of being in good health, even to the extent of rosy cheeks, whilst internally damage is occurring. Those rosy cheeks may in fact be the beginning of a rash - Lupus is Latin for wolf and the rash was sometimes compared with the facial markings of a wolf or the lesions left from a wolf bite.

Lupus can often be mistaken for something else and many patients are diagnosed only after a long process extending in some cases over several years. The severity of the disease varies from person to person, and throughout a single person's life. For some, periods of remission are intermingled with flare-ups of the disease.

Although there are many characteristic symptoms, it is worth remembering that, because it is a highly individual disease, few people would develop all these conditions.

Some of the symptoms may include:

- ◆ Fatigue, weakness, lack of energy
- ◆ Joint pain and swelling
- ◆ Skin rashes
- ◆ Fever

- ◆ Hair loss
- ◆ Sun sensitivity
- ◆ Recurrent spontaneous abortions
- ◆ Anaemia
- ◆ Swollen glands
- ◆ Depression or seizures
- ◆ Organ involvement resulting in Pleuritis (inflammation in the lungs), Nephritis (inflammation in the kidneys) or Pericarditis (inflammation in the heart)

Discoid Lupus is the name given to the disease when it is confined to the skin. As with SLE, the rashes vary in their colour and appearance and generally occur in sun exposed areas – the typical butterfly rash is a red scaly eruption over the cheeks and bridge of the nose.

The commonest part of the body targeted is the joints. This can produce pain, which moves from joint to joint without any swelling or a more fixed form of arthritis where there is joint swelling, usually in the small joints of the hands.

Severe organ involvement does occur, but fortunately only in a minority of patients.

### **Other Connective Tissue Diseases**

Lupus is related to other connective tissue disorders such as Rheumatoid Arthritis, Sjogren's Syndrome, Scleroderma and Polymyositis. Most people are aware of Rheumatoid Arthritis, or inflammation of the joints. Briefly, Sjogren's Syndrome is a disease characterised by dry eyes and mouth and results from inflammation of the tear and salivary glands; Scleroderma is characterised by scar tissue formation and shrinkage of the skin; and Polymyositis is an inflammatory muscle disease that causes weakness of the muscle.

### **Prognosis**

With treatment and lifestyle adjustments, most people can anticipate a near normal life span. As treatment is determined by the severity of the disease, early diagnosis is

important. 80-90% of patients at 10 years are alive.

The cause, and cure, for Lupus is yet to be identified, but latest research points to an underlying genetic predisposition to Lupus that is triggered by some environmental factor.

### **Treatment**

Remember that in some, Lupus is a skin disease, in others it produces sore joints and for other people it can be a life-threatening problem with severe involvement of the kidney or nervous system. It is so variable that it is difficult to recommend one treatment for all patients so it is important to individualise treatment.

General guidelines should be followed in relation to a balanced diet and avoiding direct sunlight. The anti-malarial drugs such as hydroxychloroquine are effective therapy for mild forms of Lupus. Cortisone is commonly prescribed to patients, but not everybody needs it. The immune suppressant drugs are reserved only for severe cases.

### **Contact**

There are a number of associations across Australia that offer support and counselling to patients, family and friends of Lupus and related Connective Tissue Diseases:

The Lupus Association of NSW Inc  
PO Box 89  
North Ryde NSW 1670  
Phone (02) 9878-6055 or 1800-802-088  
Email [lupusnsw@ozemail.com.au](mailto:lupusnsw@ozemail.com.au)  
Website [www.lupusnsw.org.au](http://www.lupusnsw.org.au)

Victorian Lupus Association Inc  
GPO Box 811F  
Melbourne VIC 3001  
Phone (03) 9650-5348 or 1300-556-000  
Email [info@lupusvic.org.au](mailto:info@lupusvic.org.au)  
Website [www.lupusvic.org.au](http://www.lupusvic.org.au)

Lupus Australia Queensland Inc

PO Box 974  
Kenmore QLD 4069  
Phone (07) 3878-9553  
Fax (07) 3878-9557

Lupus Association of Tasmania Inc  
PO Box 639  
Launceston TAS 7250  
Phone (03) 6331-9940  
Email [lupustas@microtech.com.au](mailto:lupustas@microtech.com.au)  
Website [www.hotkey.net.au/~lupustas](http://www.hotkey.net.au/~lupustas)

Lupus/Scleroderma Support Group  
Arthritis Foundation of SA  
1/202-208 Glen Osmond Rd  
Fullarton SA 5063  
Phone (08) 8379-5711  
Fax (08) 8379-5707

Lupus Group of Western Australia Inc  
PO Box U1956  
Perth WA 6845  
Phone (08) 9224-3144  
Fax (08) 9224-3144

## PERSONAL STORY

Amanda, a young woman from Orange, was diagnosed with lupus three years ago and here she explains what lupus is and how it has affected her life. (Reprinted with kind permission from Amanda).

“Lupus is an autoimmune disorder and is best described as a disorder that causes inflammation in the small blood vessels in the connective tissue. This inflammation may cause abnormalities in the function and structure of organs such as the kidneys, heart, brain, lungs, etc.  
I was first diagnosed with lupus (or SLE) in March 1999. I had been unwell since around 1996. I was very lethargic, so much so that I was falling asleep in class (which wasn't good as I was studying for the HSC). In 1998 my symptoms became worse as I was now experiencing severe joint pain and one day I couldn't even lift my arm. The day after my

18<sup>th</sup> birthday in 1999 is when things became really bad. I couldn't keep a thing down, not even water, which resulted in me losing 10kg in two weeks (I wish I could do that now). I was finally sent to Westmead Hospital in Sydney on March 31, 1999 where I underwent a kidney biopsy, which allowed the doctors to diagnose me with a severe case of lupus in the kidneys. It was so severe that if they hadn't found it then I wouldn't have seen Easter that year. I was scared of what they were telling me. I had no idea what lupus was so I kept telling myself that I was okay. Then came the treatment and the dreaded side effects. I was put on a large dosage of steroids, immune suppressants, blood pressure, cholesterol and fluid tablets, which were just a few of my daily cocktails. In some cases, one tablet was to counteract the effects of the other. But the worst one of all was the chemotherapy – over the past two and a half years I have had 12 infusions. All of this resulted in weight gain, hair loss, brittle bones, sleeplessness, blurred vision, depression and much more.

Since 1999, I have had three biopsies and blood tests up to three times a week and at the moment I am still fighting my current flare-up which started in December 2000. It is a daily battle for me not to let this disease get the better of me.

Lupus affects your day to day lifestyle, as you can't go out into the sun for too long because it's a major trigger for flare-ups. You also become very tired easily and any exertion takes longer to recover from. I also pick up a lot of viruses that are going around.

I was initially employed at a local newsagent but lost my job not long after I was diagnosed because of my condition. (Lupus is not contagious). I had to keep myself busy to get my mind off the lupus so I furthered my education at TAFE, which resulted in obtaining a position as a receptionist/office assistant at a local car dealership where I have been for nearly two years. During this time I have had a few flare-ups, which have resulted in me having to take time off work. But at the present time I'm improving. You have to keep a positive attitude with lupus and the Lupus Association of NSW

helps us do that with its continuing support. We even celebrate when our blood tests are better than the last ones.

At the moment there is no cure for lupus but I believe in time and with enough research and support one will be found soon."

## PROFILE 2:

### Cutis Laxa

I am Marie-Claude Boiteux, Chair and co-founder of Cutis Laxa Internationale. Cutis Laxa is a rare genetic disorder which is often misdiagnosed with Ehler-Danlos Syndrome and PseudoXanthome Elasticum.

We would like to share information with you. We are now taking a census of Cutis Laxa sufferers. We know of 9 cases in France, 4 in USA, 1 in Japan, 1 in Northern Ireland and 1 in Belgium. There might be some in Australia. Please contact us if you are a Cutis Laxa sufferer.

#### DESCRIPTION

Cutis Laxa is a connective tissue disorder characterized by a loose, hanging, wrinkled skin which lacks elasticity. The affected areas of the skin may be thickened and dark. Less than a hundred cases have been reported in the medical literature, with an equal distribution between males and females. 9 cases are known today in France. There are 5 forms of Cutis Laxa with different associated symptoms and various levels of severity.

#### Symptoms

Generally, the first symptoms of Cutis Laxa are cutaneous. The skin lacks elasticity, sometimes presenting loose folds. The loose skin is particularly obvious on the face and the neck. Children with the disorder look sad and mournful.

1. X-linked Cutis Laxa : Loose skin, mild mental retardation, loose joints, bone abnormalities (hooked nose, pigeon breast,

funnel breast), urinary tract blockages, deficiencies in lysyl oxidase.

2. Autosomal dominant Cutis Laxa : Loose skin, missing elastic fibers, premature aging, pulmonary emphysema.

3. Autosomal recessive Cutis Laxa Type I: Loose skin, pulmonary emphysema, diverticula in the esophagus, duodenum and bladder, lax and/or dislocated joints, tortuous arteries, hernias, lysyl oxidase deficiencies and retarded growth.

4. Autosomal recessive Cutis Laxa Type II: Loose skin, bone abnormalities, delayed joining of the cranial (skull) bones, hip dislocation, curvature of the spine, flat feet, excessive tooth decay.

5. Acquired Cutis Laxa : It tends to follow either a severe illness characterized by fever, inflammation and severe skin rash (erythema multiforme), or an autoimmune condition.

#### Diagnosis

The first sign of Cutis Laxa is cutaneous and very obvious. Simply examining the skin can allow the diagnosis. The determination of the form is aided by information about the associated symptoms and family histories. Sometimes it is not very easy to determine the right diagnosis between Cutis Laxa, Ehler-Danlos Syndrome and Pseudo Xanthome Elastic.

Most of the time, geneticists or dermatologists will provide the diagnosis.

#### Inheritance

As written in the Symptoms, inheritance of Cutis Laxa is different according to its form. We can only note that the autosomal recessive forms are the most common and the autosomal dominant the least.

This description of Cutis Laxa has been written by Marie-Claude Boiteux, President of Cutis Laxa Internationale, and will be published in the Federation des Maladies Orphelines booklet: "Rare Genetic Diseases: To know more about them" ( Paris, France, January 2002)

## Our Story

Cecile was born in October 1990. For the first two years of her life, there was not anything at all indicating that she was suffering from a rare genetic condition. However her dad, Jean-Louis, thought her skin was not quite right, too soft, too lax, as if somehow it was too big for her body. So, Jean-Louis and I decided to consult a dermatologist (skin specialist).

Fortunately for us, we knocked on the right door at the Hopital Saint-Louis in Paris. There Doctor Mrs Blanchet-Bardon did not hesitate for a second, her diagnosis: Cecile suffers from a rare genetic disorder, Cutis Laxa. Once we'd covered all the medical issues, we asked if we could meet other sufferers.

Unfortunately, at that time, Cecile was the only case Dr Blanchet-Bardon had come across and there were no associations concerned with this condition. We faced the unknown alone, unable to share with anybody all the upheavals this disease brought into our lives. What of our daughter's future? What difficulties would we have to confront? No one who could help us outside of the medical circles. These were tough years, during which we had to learn to live with the gaze of others and teach Cecile to be strong in front of this gaze. All our attempts at getting in touch with other sufferers through various organisations were in vain. However, within hope was still alive that may, some day ...

10 years have now gone by since Cecile's birth. The TELETHON\*, which we watched loyally from its beginning, set up its cameras on the Ile de Re where we live. It was an opportunity for us, and especially for Cecile, to participate more fully, more concretely than in the past. She took part in two documentaries where her dynamism and love of life exploded on the screen. Cecile's proven motivation pushed us to start looking

again for other sufferers. We had not long bought a PC and thanks to the internet I finally found two cases of Cutis Laxa (1 in the USA, the other in Japan) mentioned on a US site for family contacts. I could not believe my eyes. Finally, we were not alone anymore. Stimulated by this discovery, I visited other sites and found another case in Northern Ireland.

We exchanged our first e-mails with great emotion. Friendships started to flourish. We shared our tears and laughter ... but we are flung at the four corners of the earth and the language barrier does not facilitate our exchanges.

In the area around Angouleme, Melissa and her parents saw Cecile on the television during the Telethon. For 14 years, they too had been alone with Cutis Laxa. They managed to get a letter to us. Cecile was in hospital when she learned that she was not alone in France anymore, and she cried tears of joy.

In Brittany, Tifenn also saw Cecile and gets in contact with us. Then Nathalie and Mireille joined us after Cecile took part in the show 'Ca se discute' (Let's talk about it).

At that point we were a group of 8 families (5 in France, 3 abroad), with a total of 9 sufferers.

On 11th November 2001, we started "Cutis Laxa Internationale" to put to an end to the despairing loneliness of Cutis Laxa sufferers.

Today, other sufferers have joined us, in France and the USA. We now know of 15 sufferers. Others will join us, I'm sure.

Marie-Claude Boiteux  
Chair, Cutis Laxa Internationale

### OUR AIMS AND OBJECTIVES

- ❖ To break the isolation of sufferers and their families in France and abroad.

- ❖ To bring together all the people likely to support our actions.
- ❖ To look for as many sufferers from Cutis Laxa as possible throughout the world to create the necessary mass for research.
- ❖ To assemble as much of the available data on Cutis Laxa.
- ❖ To inform the media and the medical world about Cutis Laxa.  
To get Cutis Laxa recognised as an orphan condition.
- ❖ To work towards financial support for research.

**CONTACT: Cutis Laxa  
Internationale  
MCJLBoiteux@aol.com**

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## CONFERENCES

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### **Genetic Support Network of Victoria CONFERENCE & EXPO**

Date: May 3 & 4, 2002 Venue: Royal Children's Hospital, Melbourne. This is the Genetic Support Network of Victoria's (GSNV) first conference. It will be a chance to meet other people who are overcoming genetic challenges – some similar to yours, others different. Some issues to be discussed include:

- ❖ Relationships between support groups and professionals
- ❖ Protecting genetic information
- ❖ Acknowledgment of patient contributions in genetics

Enquires: GSNV, (03) 8341 6315  
gsnv@murdoch.rch.unimelb.edu.au

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**Prader-Willi Syndrome Association of  
NSW Inc** 8<sup>th</sup>  
**Australasian Prader-Willi Syndrome  
Conference** Date:  
April 27 & 28, 2002. Venue: Carlton

Crest Hotel, Sydney. Prader-Willi Syndrome is a rare genetic disorder that affects 1:10,000. Little is known about Prader-Willi Syndrome. It is a recognized pattern of altered growth and development, which occurs from birth and is present throughout life. The conference will bring a wealth of information to families, medical professionals and disability support teams, which will assist them in understanding this complex syndrome and our kids.

Enquiries: Louise Soames (02) 9525 6238  
Website: [www.aust.pws.org.au/conf](http://www.aust.pws.org.au/conf)

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**IDEAS EXPO 2002** is coming up. There will be a wide variety of workshops and exhibits from organizations including;

- ❖ Cares NSW
- ❖ Brain Injury Association
- ❖ Anti-Discrimination Board
- ❖ People with Disabilities
- ❖ Epilepsy Association

For more information about the IDEAS Expo workshops, please contact Sue on 1800 029 904 or [commea@ideas.org.au](mailto:commea@ideas.org.au)

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### **6<sup>th</sup> National Deafblind Conference**

Date: July 12 & 15, 2002 Venue: The Lidcombe Catholic Workmen's Club, Sydney.  
Enquiries: Deafblind Association Tel: (02) 4957 2741

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### **Australian Huntington Disease Association (Inc.) WA First National Conference**

Date: April 18, 2002.

Venue: The Esplanade Hotel, Fremantle.

This conference will provide a unique opportunity for members of the West Australian Huntington's community to hear international, interstate and local keynote speakers talk on different aspects of Huntington's including: behaviour, care, communication, and Pre-implantation genetic diagnosis. It will also make a significant contribution toward continuing education of professionals, health care workers and service providers working in the area of Huntington Disease.  
Enquiries: Tel (08) 388 3200

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## OVERSEAS NEWS

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### 8<sup>TH</sup> INTERNATIONAL CONFERENCE ON LOWE SYNDROME

Date: June 28 – 30, 2002. Venue:

Oak Brook, Illinois (near Chicago)

The 8<sup>th</sup> International Conference will bring together families affected by Lowe syndrome, friends and relatives, professionals, and other interested persons for a series of presentations and discussions on subjects relating to Lowe syndrome.

Parents are encouraged to bring their children. Free childcare will be provided during all formal sessions. Enquires: Lowe Syndrome Association, 222 Lincoln St., West Lafayette, Indiana 47906, USA. Tel: (0011-1) 756-743-3634 E-mail:

[info@lowesyndrome.org](mailto:info@lowesyndrome.org)

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**NATIONAL ORGANISATION FOR  
RARE DISORDERS (NORD) Inc (USA)  
NEW RESEARCH GRANTS  
AWARDED!**



The Massachusetts based biotechnology company, Transkaryotic Therapies (TKT), committed US \$1 million to NORD to encourage scientific research on lysosomal storage diseases. This, along with additional support from Genzyme Corporation, allowed

NORD to create the Roscoe Brady LSD Fellowships.

The first fellowships awarded, totaling US\$337,680, have gone to researchers in the U.S., Japan and Brazil. This year's winners will explore the causes of Fabry, Krabbe, Hunters, Gaucher and Tay-Sachs disease. Lysosomal storage disorders are categorised by an abnormal build-up of various toxic materials in the body's cells that affect the skeleton, brain, skin, heart, and central nervous system. There are currently no effective treatments for the vast majority of these diseases.

Inquiries regarding future funding opportunities may be directed to Linda Cataldo, NORD, at 0011-1-203-746-6518 or E:mail [Lcataldo@rarediseases.org](mailto:Lcataldo@rarediseases.org) or visit the website: [www.rarediseases.org](http://www.rarediseases.org)  
Reprinted from *Orphan Disease Update* Volume 20, Edition 1, Winter 2001/2002.

### Types of genetic mistake

**Correct sequence:** (also known as the 'wild type')

THE CAT AND THE RAT ARE FAT

**Transposition:** THE

ACT AND THE RAT ARE FAT **Missing**

**letter:** THE CAA NDT

HER ATA REF AT **Repeated letter:**

THE CCC ATA NDT HER ATA REF

**Substituted letter:**

THE COT AND THE RAT ARE FAT

Reproduced from Genetic Interest Group  
([www.gig.org.uk](http://www.gig.org.uk))

**AGSA/ConnecteD  
Personal Health Folder**

This is a unique folder designed to help parents organise all the information and reports confronting them when the diagnosis of a genetic disorder is made. It can be used by anyone wanting to keep personal health information. Although conceived by AGSA, this edition carries the logo of ConnecteD. It has a connective tissue motif. It will also be valuable for adults with any chronic disorder but particularly for adults with musculo-skeletal disorders (eg arthritis or osteoporosis). Cost: \$34 (GST incl.)  
Enquiries: Kids Health, The Children's Hospital at Westmead. Tel (02) 9845 3585 Fax (02) 9845 3562 Online shop: [www.bandagedbear.com.au](http://www.bandagedbear.com.au)



“Making the right  
connections since 1988”