

**KEEPING  
IN  
TOUCH**



**November  
2007**

**Cornelia de Lange Syndrome Association (Australasia) Inc.**

Authority to Fundraise: NSW CFN 15201  
Donations of \$2 and over are Tax Deductible  
DGR 419321 ABN 97 070 990 653

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**Websites:** Australasia: [www.cdlsaus.org](http://www.cdlsaus.org)  
International: [www.cdlsworld.org](http://www.cdlsworld.org)

**Online support groups:** OZ/NZ online discussion group: [oznz-cdls@yahogroups.com](mailto:oznz-cdls@yahogroups.com)  
(register via the link on the [www.cdlsaus.org](http://www.cdlsaus.org) homepage)  
International Online Support Group: [www.cdls-support.org](http://www.cdls-support.org)

## **From the editor**

Australia's Federal election is fast approaching. When making your choices, please consider the Carers Alliance whose candidates are standing for the Senate. Services to people with disabilities and their carers is an important issue for us and for the whole community. This is a chance to make a difference. Details later in this issue.

*Joanne*

## **ASSOCIATION NEWS**

### **Membership**

**Welcome to our newest members** from: The Philippines, South Australia and Queensland.

### **Donations**

Thank you to everyone for their generous gifts and special thanks to the generous anonymous donor of \$2,000.

**PETER CRAWFORD'S FUNDRAISER** through the Chief Minister's Command Performance Concert raised \$1,500.

**PRINTING AND POSTAGE OF KIT:** ComputerShare

**WEB SPONSORS:** Rollo and Humphrey families

## Claire Craig (New Zealand)

Claire passed away on 28 September 2007. She was mum to Andrew, Emma, Paul and Mark. Wife to Ian but had recently separated.

Claire was special to us. She was the first parent we met who had a child with CdLS, Emma and as a parent you never forget that. You realise you are no longer alone. Claire loved the social life, meeting for lunches, afternoon teas etc and every school holidays she welcomed us to her house. Claire was a firm believer in the whole family being involved with any gatherings, siblings and all (A true CdLS trait) and it is through this that we got to know her children so well.

Claire was a battler and had many hurdles to cross during her life, she never let this get her down and could always see the bright side of life. She only wanted the best for Emma making sure she had the best care. Many of us know the battles you have for education, health, for your CdLS child and Claire's mission was "only the best".



As Claire's health deteriorated she struggled to care for Emma but with great wisdom, she saw that Emma needed to go into full time care. Claire saw that if Emma moved to a smaller town she would be better cared for than in Auckland. A tough decision to have her move out of Auckland, but Claire knew this was the best. A mother's instinct.

Claire loved the CdLS group both nationally and internationally. Through the support of a local CdLS family she travelled to international conferences in England, Australia and local get togethers. Claire was really the first person in NZ who attempted to get a CdLS group formed and running. It was the days before the internet so it was difficult to do, but she achieved a lot with the resources available. It is the work that she started that we carry on today. Claire's CdLS involvement was recognised at her funeral by having Carol Duffee give a moving eulogy.

The get togethers we had at Claire's - you don't realise how special these gatherings are until you can look back and realise you have shared many a moment with other parents but also become part of the other children's lives as well. Andrew, Paul and Mark have become part of the CdLS family and are proud of it and what it means for their sister. Two weeks after her funeral CdLS parents gathered together to attend the musical 'Hair' in which her son Paul was one of the leads in the show and Claire would have been so proud.

I can't say may you rest in peace Claire, you are in peace. Emma is in great care, the boys are starting their careers, Ian is forging a new life, the CdLS support group is running strongly in NZ and you found your God. Everything is done so you are in Peace.

From the CdLS family

## International CdLS Conference 2007 – Canada

The conference hosted by CdLS Canada was a tremendous success. The venue will be impossible to better. The hotel overlooked Niagara Falls and was in the centre of a district of entertainment for people of all ages. Socially the program enabled participants time and places to bond. The planned entertainment was magnificent with a spectacular opening dinner and black light show performed by the cast of Gypsy Theatre, and the Gala was a themed 007 Bond evening where guests dressed to the nines and were kept on the dance floor until the wee hours.

The program was dedicated to issues of “Living with CdLS”. Siblings had their own separate program from the rest of the family, within which were sessions for grandparents, mums, dads & professional carers. A hands-on music therapy session was particularly popular. All the children and parents were invited to join in with percussion instruments – mostly drums and interesting hand-made-out-of-everyday-junk shakers. A performance at the Gala saw many doctors join in the fun. Medical sessions covered all aspects of CdLS from babies to adults. Detailed reports are being prepared and will be posted as a separate mailing.



Everyone was included in the music therapy

SAC and Federation Council meetings were pressed for time despite having twice as much time allocated for meetings as previous conferences. I think this partly shows how much there is to talk about between the medical advisors and the national leaders.

The Federation finalised its Constitution which has been a long process of discussion and decisions, trying to encompass the needs and legal requirements of the various countries involved. Congratulations to the people involved in this work. Alan Peaford (UK) continues the work of translations of CdLS information. Peter was sorely missed at the meetings but he had prepared many pages of financial records and budget for the following two years for Jen to present on his behalf. Rose took the minutes of the meetings.

**We look forward to meeting again in Brighton, England in July 2009.** More details in future issues of KIT.

*Jenny Rollo*



Dr Alex Levin gets into the rhythm



The children loved being involved



**Federation of CdLS Groups represented:**  
(from top left to bottom row)

USA, Poland, Denmark, Portugal, Canada, Holland,  
Italy, Spain and Spanish speaking countries, France,  
UK, Germany, Australia.

## *More from the International Conference*

Early this year I was honoured to be asked to attend the 2007 International Conference in Canada as our President, Peter, was unable to attend due to ill health. Thankfully Peter has made a full recovery since, so I'm glad that I didn't needlessly punish myself with feelings of guilt for my good fortune.

Jen, Steve, his mate Alan, and I arrived a few days early and helped out with a few preparations. We also helped on the registration desk which gave me a great opportunity to see families as they arrived. It was very exciting to catch up with families who I'd met at previous conferences; and great to meet so many new families from so many countries. However, it is always the family members with CdLS who continue to inspire me as I see them grow and blossom from year to year.

Whilst I missed my family, I was able to attend doctor consults, professional sessions and "some" social events, without worry. The Mothers' Workshops were very uplifting sessions as we all shared our experiences and common concerns for our children's future. I gained more knowledge from the professional sessions which I have since discussed with Laura's paediatrician who has acted on this information.

The highlight of the Conference for me though, was being able to attend Federation Council meetings. I am grateful to this very dedicated group, who through their hard work and persistence over the years, have been responsible for creating the international group of CdLS-World, which supports families today. Thanks to this group's commitment, planning and foresight, families all over the world, are provided with up to the minute medical information, support and hope for the future.

Rose



Rose, Lisa, Claudia, Jen & Steve with the American Falls in the background.

## SCIENTIFIC ADVISORY COUNCIL

The Scientific Advisory Council is made up of medical and other professionals who take responsibility for the shared knowledge of specialties. Its goal is to help families, researchers and other professionals understand the complexities of the syndrome. The Council also includes “Professional Directors” from countries around the world who represent the Federation among their own professional communities and are a focal point for SAC information within that country.

<p><b>Chairman:</b> Angelo Selicorni (Italy PD)</p> <p><b>Education:</b> Mary Morse (USA) Emanuele Basile (Italy)</p> <p><b>Vocational Rehabilitation/OT/PT</b> Amy Metrena (USA) Milagros Cordero (USA)</p> <p><b>Psychology:</b> John Morse (USA)</p> <p><b>Behaviour:</b> Tom Gualtieri (USA) Chris Oliver (UK)</p> <p><b>Psychiatry:</b> Eileen Ahearn (USA) Marco Grados (USA)</p> <p><b>Speech &amp; Language/feeding:</b> Marjorie Goodban (USA) Cheri Carrico (USA)</p> <p><b>Ophthalmology:</b> Alex Levin (Canada PD) Ken Nischal (UK)</p> <p><b>Research Genetics:</b> Laird Jackson (USA) – Emeritus PD Iain Krantz (USA) Tom Strachan (UK)</p> <p><b>Research: Developmental Biology</b> Anne Caloff (USA)</p> <p><b>Clinical Genetics:</b> Toni Kline (USA PD) Angelo Selicorni (Italy PD) David Fitzpatrick (UK PD) Armand Bottani (Switzerland PD) Meredith Wilson (Australia PD) Raoul Hennekam (Netherlands PD) Valérie Cormier-Daire (France PD)</p>	<p><b>Emeritus Professor:</b> Laird Jackson (USA)</p> <p><b>ENT:</b> Bob Sataloff (USA) Paola Marchisio (Peds, Italy)</p> <p><b>Paediatrics:</b> Jolanta Wierzba (PD, Poland)</p> <p><b>Orthopaedics:</b> Antonio Memeo (Italy) Paul Sponseller (USA)</p> <p><b>Neurophysiologist/Neurology:</b> Carsten Bonnemann (USA) José Pedro Vieira (Portugal PD)</p> <p><b>Radiologist:</b> Mark Kliewer (USA)</p> <p><b>GI Medical:</b> Carol Potter (USA) Peter Gillett (UK) Peggy Marcon (Canada)</p> <p><b>GI Surgery:</b> Sergio Luzzani (Italy)</p> <p><b>Dentistry:</b> Dick Mungo (USA) Doug Clemens (USA)</p> <p><b>Nutrition:</b> Joni Rampolla (USA)</p> <p><b>OB/Gyn:</b> Natalie Blagowidow (USA) Shoko Shimizu (Japan)Shoko Shimizu (Japan)</p> <p><b>Neonatology:</b> Luigi Memo</p> <p><b>Anaesthesia:</b> Aaron Zuckerberg (USA)</p> <p><b>Cardiology:</b> Anna Maria Colli</p>
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SAC representatives in Canada

## *Fundraiser 2008*

Our first major CdLS fundraiser in eight years is shaping up to be the social event for 2008.

With thanks to Gypsy Theatre of Fort Erie, Ontario, Canada, a captivating night of theatre will be held in Sydney in mid 2008. CdLS Canada President, sister to Michael Feeney (CdLS) and actor extraordinaire, Bernadette Feeney (Dalingwater) will be presenting

### *Shirley Valentine*

Bernadette has been touring with Shirley Valentine for many years and is now delighted to present this one woman play for CdLS Australia for one night only.

There will be a silent and live auction, supper and surprises. Donations of prizes for raffles and auction are very welcome. Please contact Jenny.

More information about date, venue & how to buy tickets next KIT.

## CdLS Mini Conference 2008

The CdLS Association is pleased announce that plans are well underway for the CdLS Clinic Day in Adelaide.

**Who:** All CdLS families and interested professionals are invited to attend.

**When:** Weekend of 16/17<sup>th</sup> February 2008

**Where:** Chifley on South Terrace, Adelaide

**Focus:** Behaviour. Prof. Chris Oliver from the UK SAC will be presenting his latest research results and meeting with families to discuss individual problems. Other speakers to be advised.

We will be applying for grants to help families with their expenses, although there is no guarantee of success in this area. As usual we will keep the costs to the barest minimum. Please contact Jenny to indicate your intention to attend, and whether you will need financial help to do so. The CdLS Association brings this meeting to Adelaide to particularly encourage attendance of families from the south of the continent, although everyone is welcome to attend.

Feedback from previous conferences indicates that families want more time to get to know each other. This meeting is therefore planned with more free time for this purpose. Formal meetings are on the Saturday morning only, with the afternoon (and Sunday morning if necessary) set aside for doctor consultations.

Details, including registration, etc will be posted in January. You may book your accommodation now by contacting the hotel directly and **quoting CdLS Association**.

Phone 1300 650 464, email [reservations.southterrace@chifleyhotels.com](mailto:reservations.southterrace@chifleyhotels.com) or online at [www.chifleyhotels.com](http://www.chifleyhotels.com)

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### President's Report 2007

This year I begin my Report by noting that we successfully conducted a national conference in September last year, have participated in the International Conference in Canada during this year and are well into the planning stages of holding a Clinic Day in Adelaide in February next year with, hopefully, participation from families from Western Australia, Tasmania and Victoria as well as South Australia

I would like to invite all members to join me in thanking our state co-ordinators, Joanne Argent, the editor of *Keeping in Touch*, our committee, our website manager, Rose Humphrey, our wonderful Secretary, Jenny Rollo, our Treasurer, Brett Howe who have continued to serve our CdLS community with dedication and skill.

The OZNS on-line group continues to grow and provide mutual support to its participants as well as proving a rallying point for political action.

The National Conference in September last year was no mean achievement. The members who assisted in preparing for it and running it grew closer together. Those who participated were rewarded by the sharing of common experience, by that confirmation that we are not alone in our struggles to cope and by the friendly exchange of mutual support that is the sign of a vital, strong and successful organisation.

The clinic day planned for Adelaide next February will provide more opportunities for our members to benefit from the expertise of Professor Chris Oliver and other health professionals as well as to enjoy the exhilarating, comforting experience of getting together as families.

On the international level I have asked Jenny Rollo to report on the Conference in Canada, which for health reasons I was unable to attend.

Since the Conference in July, there appears to be some hope that Bulgaria may set up a national association and become a member.

Both at home and abroad, the challenge remains to achieve better outcomes for our CdLS community.

Peter Crawford  
President  
22 October 2007

## **CdLS Management Committee 2007/2008**

The dedicated CdLS management committee continues into 2008 without change. Grateful thanks to these people who work so hard as volunteers for Australasian CdLS families.

**President:** Peter Crawford (ACT)

**Vice President:** Steve Sandilands (WA)

**Treasurer:** Brett Howe (NSW)

**Secretary:** Jenny Rollo (NSW)

### **Ordinary Committee Members:**

Carol Duffee (NZ), Claudia Dale (VIC), Lynne Woods (VIC), Rose Humphrey (QLD) & Joanne Argent (NSW)

## **Assessment of Hand Function**

In response to a question from a Victorian family about their son's hand function Dr Tonkin has informed us of two clinics which do such assessments.

The Royal Melbourne Children's Hospital conducts a paediatric hand clinic. They have two senior consultants and hand therapists who are experienced in dealing with these conditions.

The Congenital Hand Clinic is held every second Friday at the Children's Hospital at Westmead (Sydney). It also has experienced hand therapists.

Both groups would be able to provide an opinion as to whether any intervention would be beneficial to improve function. Contact details are available by ringing the hospitals.

## Australian Elections: Vote 1 Carers Alliance in the Senate

Exciting political times are ahead for Australians who have taken on the role as carer for a loved member of their family. Anyone, anytime could find themselves in the role of carer through birth, old age, dementia, disease or accident. These issues affect ALL Australians.

The Carers Alliance political party was launched during Carers Week in October. These two events saw a great deal of coverage in print, on TV and the internet. (Check out youtube for a plethora of political information both serious and fun.) The Carers Alliance is fielding candidates for the Senate in the upcoming Federal election. (See below) Their purpose is to ensure people with disabilities and their families have the services they need but have thus far been sadly neglected by successive governments. For the first time we have a real chance to have a voice in Canberra. How can you help? Tell your friends and family about the Party, and ask them to show their support by voting accordingly. The senate vote will not change the outcome of who, of whichever party, ends up as Prime Minister.

For more information and more details about the candidates go to the Carers Alliance web site [www.carersalliance.org](http://www.carersalliance.org)



YOUR CANDIDATES ARE:

### New South Wales

**Mary Lou Carter**, No. 1 Candidate in NSW.



*"Caring is only a burden when there are no services or support"*

**Nell Brown**, No. 2 Candidate in NSW.



"It is time for Australians to stand united and demand that we become a just society, one that concerns itself with the way it treats all people"

Late breaking news: **Katrina Clark** is now No 3 Candidate in NSW

## Queensland

**Felicity Maddison AM**, No. 1 Candidate in QLD.



Felicity was appointed as a Member in the Order of Australia in 2002 for services to people with disabilities, their families and carers.

**Robert Gow**, No. 2 Candidate in QLD.



At nearly 21 years of age Robert has already experienced years in the role of unpaid family carer. Siblings need to get a fair go too!

## Western Australia

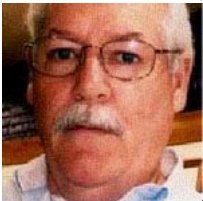
**Thomas Harry John Hoyer**, No. 1 Candidate in WA



Working towards education & awareness of mental health in the "Beyond Blue" program, Tom has gained a significant insight into the frustration of mental illness sufferers and their carers.

## Victoria

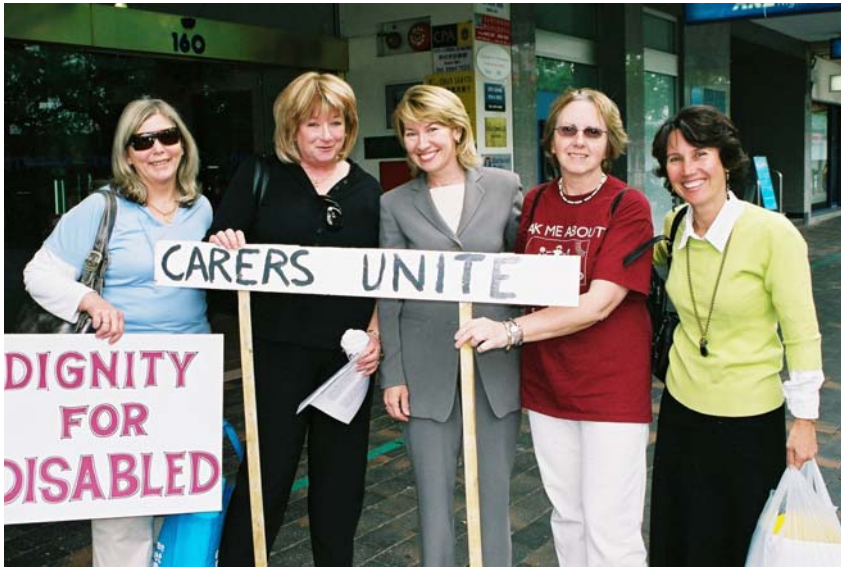
**John Newman**, Candidate in VIC.



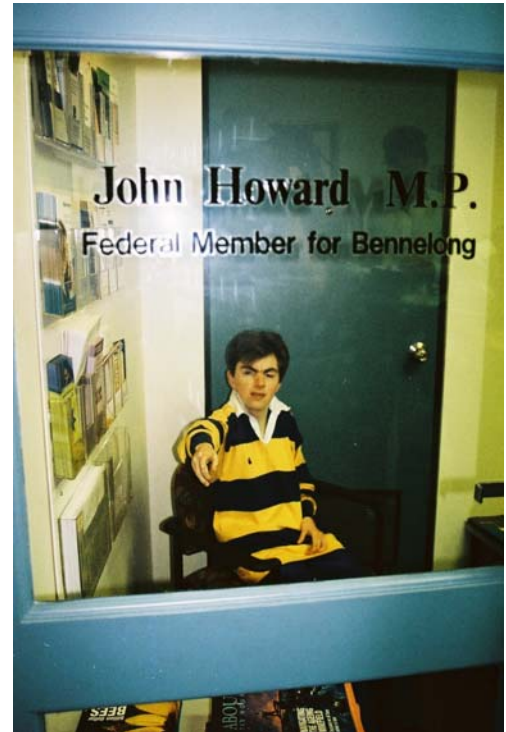
John is a 60 year old carer for his aging mother. He believes all carers irrespective of disability or age be fairly and equally served by all governments and providers.

## Protest Rallies

Carer protest rallies during September and October were held at the offices of the Prime Minister in Sydney. These attracted a lot of media attention with journalists coming from as far away as Melbourne. The Prime Minister's assistant, Stephen, patiently listened and took notes from the file of carers and people with disabilities who wished to register their complaints. All carers spoke from the heart of their difficulties of trying to cope without adequate services to help them. One young woman who has Down Syndrome registered her protest: "I want to leave home like my sister did". Eloquent words which prove that people with developmental delay need to be given a chance to live their lives away from the parental home.



Labor candidate for Bennelong in the House of Representatives, Maxine McKew, joined Carers during the protest rally in October. From left: Marilyn Jones and Lyn Allen from RASAIID, Maxine McKew, Jenny Rollo, and Carers Alliance No 3 candidate for the Senate, Katrina Clark.



David Rollo at the sit-in at the Australian Prime Minister's office in September.

# **SIBLING NEEDS -- HELPFUL INFORMATION FOR PARENTS**

By Derenda Timmons Schubert, Ph.D.  
Pacific Northwest Children's Services  
Waverly Children's Home  
3550 SE Woodward Avenue  
Portland, OR 97202

## **I. DEVELOPMENTAL CONSIDERATIONS**

*WHAT DO YOU TELL.....*

### **1. PRESCHOOLERS (BEFORE AGE 5)**

Children in this age group are unable to articulate their feelings about things, so they will likely show their feelings through behaviors. They will be unable to understand the special needs of their sibling, but they will notice differences and try to teach their brother or sister. Children of this age are likely to enjoy their sibling because they have not learned to be judgmental, and their feelings toward their siblings will likely be linked to "normal" sibling interactions.

### **2. ELEMENTARY SCHOOL AGE (6 - 12)**

These children start venturing out into the world and become acutely aware of the differences between people. They have the ability to understand a definition and explanation of their sibling's special need as long as it is explained to them in terms they can understand. They may worry that the disability is contagious or wonder if something is wrong with them, too. They may also experience guilt for having negative thoughts or feelings about their sibling as well as, guilt for being the child who is not disabled.

Some typical responses of children this age are to become OVER helpful and well-behaved or to become non-compliant in order to obtain a parent's attention. Throughout this age span, the children will have conflicting feelings about their sibling. This happens in sibling relationships that do not include a disability, too.

### **3. ADOLESCENTS (13 - 17)**

Adolescents have the capability of understanding more elaborate explanations of the particular disability. They may ask detailed and provocative questions. The developmental task of adolescence is to begin discovering oneself outside of the family. At the same time, conformity with a peer group is important. Therefore, for children this age having a sibling who is different MAY be embarrassing in front of friends and dates. They may feel torn between their desire for independence from the family and maintaining a special relationship with their sibling. They may resent the amount of responsibility, and they may begin worrying about their sibling's future.

## **A. EDUCATE YOUR CHILDREN**

PROVIDE INFORMATION TO THE CHILD ABOUT HOW THE CONDITION IS EVALUATED, DIAGNOSED, AND TREATED.

- THE CHILDREN NEED TO KNOW WHAT THE DISABILITY IS AND WHAT TO EXPECT
- EXPLAIN STRENGTHS AND WEAKNESSES OF THE CHILD WITH THE DISABILITY
- EXPLAIN WAYS TO INTERACT WITH SIBLING
- EXPLAIN WAYS TO HELP WITH SIBLING

## **B. BALANCE TIME SPENT WITH CHILDREN**

- ENCOURAGE CHILD TO HAVE ACTIVITIES UNIQUE TO HIM/HER
- PARENTAL PARTICIPATION IN ACTIVITIES OUTSIDE THE DISABILITY WORLD/COMMUNITY.
- PARENTAL RECOGNITION OF CHILD'S STRENGTHS AND ACCOMPLISHMENTS

## **C. OPEN DISCUSSION**

- OPEN DISCUSSION IN THE FAMILY SHOULD EXIST WHERE MEMBERS' POSITIVE AND NEGATIVE FEELINGS ARE EXPRESSED
- DISCUSSION OF WAYS TO COPE WITH STRESSFUL EVENTS SUCH AS PEERS AND PUBLIC REACTION, AS WELL AS, UNEXPECTED CHANGES IN FAMILY PLANS, EXTRA HOME RESPONSIBILITY

## **D. SIBLING GROUPS**

- PARTICIPATION IN A GROUP FOR SIBLINGS ALLOWS THE CHILDREN TO MEET OTHERS WHO ARE IN THE SAME CIRCUMSTANCE
- PROVIDES CHILDREN WITH THE CHANCE TO DISCUSS FEELINGS WHICH MAY BE DIFFICULT TO EXPRESS TO THE FAMILY

## **II. WARNING SIGNS**

### **A. DEPRESSION**

- CHANGE IN CHILD'S SLEEPING HABITS
- CHANGE IN CHILD'S EATING HABITS
- SENSE OF HELPLESSNESS/HOPELESSNESS
- CONTINUED SENSE OF IRRITABILITY
- MENTIONS HURTING SELF (I.E. "I WISH I WAS DEAD")
- DIFFICULTY MAKING DECISIONS OR CONCENTRATING
- LACK OF PLEASURE IN ACTIVITIES
- SOCIAL WITHDRAWAL
- LOW SELF-ESTEEM

### **B. ANXIETY**

- EXCESSIVE WORRY
- INCREASED ENERGY LEVEL WITHOUT A PURPOSE
- TEARFUL AT SLIGHTEST FRUSTRATION
- HAS DIFFICULTY SEPARATING FROM PARENTS
- SLEEPING PROBLEMS OR CHANGE IN SLEEPING HABITS
- CHANGES IN EATING HABITS
- SCHOOL PHOBIA
- WORRY ABOUT HEALTH OR WELL-BEING OF FAMILY MEMBERS
- SOMATIC SYMPTOMS (I.E. STOMACHACHES AND HEADACHES) 10. PERFECTIONISM

If your child displays a number of these symptoms for a prolonged period of time (2 weeks or more), it may be advisable to discuss the situation with the child's pediatrician or a local mental health professional.

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**RESOURCE OF INFORMATION** SIBLING INFORMATION NETWORK  
DEPARTMENT OF EDUCATIONAL PSYCHOLOGY  
BOX U-64, THE UNIVERSITY OF CONNECTICUT  
STORRS, CT 06268, U.S.A.  
(203) 486-4034

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