



# Families in CHARGE



Ok, Let's **bee** serious...you know you all want to **bee** at this conference! So buzz on over now to the CHARGE website for registration forms at [www.chargesyndrome.org.au](http://www.chargesyndrome.org.au)

- C** coloboma of the eye  
**H** heart anomalies  
**A** atresia of the choanae  
**R** retardation of growth  
**G** genitourinary system anomalies  
**E** ear anomalies and hearing loss

Feel free to contact us for brochures, handbooks, videos, literature, parent support or to make a donation.

*CHARGE Syndrome Association of Australasia Ltd is a registered charity with DGR status and all donations are tax deductible.*

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#### Families in CHARGE Newsletter

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## The latest buzz on the **B** in CHARGE Conference

The **B** in CHARGE Conference is fast approaching and shaping up to **bee** a fantastic experience that must **bee** included in your calendar of events! There are now 4 international keynote speakers - David Brown, Tim Hartshorne, Jeremy Kirk and Kasee Stratton - plus 2 of our Men from Oz - George Williams and Rob Last!

Most readers will **bee** familiar with these key professionals in the CHARGE community...those new to our CHARGE family, please visit the website at [www.chargesyndrome.org.au](http://www.chargesyndrome.org.au)

for more information on our key speakers. Now on the website is information on getting financial assistance to attend, as well as an updated program.

The venue at the Esplanade Hotel in Fremantle is superb; the accommodation is great; the program is terrific and the people you will meet for the first time, or will meet again, will **bee** the highlight! Not only will this conference **bee** hugely informative, it will also **bee** a lot of fun!

**Be**cause, there is a CHARGE family...and once stung, you'll **bee** back! So buzz on over to our website and register now!

#### CHARGE Syndrome Association of Australasia Ltd 2008/2009 Officers

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You can find contact details on our website:  
[www.chargesyndrome.org.au](http://www.chargesyndrome.org.au).

## Families in CHARGE

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### Working Out and Having a Ball

By Jennifer B. Buckley

Remember when you were a child and running around the playground, swimming in the community pool, or building a sand castle was fun? Little did you know you were not only having fun, but getting a workout too. With all the challenges we face on a daily basis; caring for our loved-ones, working and cleaning, imagine putting more fun back into your life through exercise. It wouldn't seem like another task on our "to do" list, it would feel more like play time, but with health benefits. Right now, sitting in your living room with a tub of Hagan Daaz and watching your favorite prime time drama may be your way of relaxing, only to feel guilty later for consuming a pint of ice cream. Well, relax and have fun minus the guilt by engaging in your favorite physical activity.

First, you need to change the way you think about exercising. Believe that it can be an exhilarating, adventurous, and energy-boosting experience, not to be taken for granted. Next, acknowledge the fact, you deserve to celebrate life with a fun-filled work out. It's a chance for you to care for you physically, emotionally and mentally. Also, when you are through having fun (a.k.a. exercising) reflect upon how good it made you feel and make a conscience effort to remember that feeling, it will

help you stay motivated.

Lastly and most importantly, take the stress out of exercising. You don't have to break any records, win a gold medal and loose 25-pounds by the end of the workout, just have FUN. Here are some ideas to help you start enjoying yourself while exercising.

Go for a leisurely walk with a good friend you rarely get to see. This idea is often suggested but rarely implemented so remember now you have different motives, to have fun not burn calories.

Try a physical activity you've never tried before or haven't done in a long time. How about ballroom dancing or yoga? There are usually studios in every city at various price and time ranges. A good idea is to call around for quotes.

Teach your children a new sport like kickball, baseball or Frisbee. An active parent yields active children so be a shining example.

Go on an exploration to a place you've never been. Get all geared up with hiking boots, water bottle and bug spray. Put all your adventure needs in a backpack and off you go. It could be a place near your home or 20 minutes away that you've been wanting to see. Maybe it's a beautiful tree lined neighborhood or a neat historical park laced with raccoons and

squirrels. Go ahead and choose, be adventurous.

One of the biggest complaints about exercising is lack of time and energy. Well, all you need to do is get through the door. By taking the stress out of exercising and putting back in the fun, you have laid the foundation of a completely new way of working out. Just go out and have fun. It doesn't matter for how long or what you do. Start by skipping back and forth from your car to the front door three times or chasing your dog around the yard for five minutes whatever you feel compelled to do. When you were a child, you didn't think about the reason why you kept jumping on and off a log or pretended to be a black belt in karate while torturing your younger brother, you simply did it and that's having fun.

Barbara Collins, an office administrator, admits to playing her favorite old time records, opening all the windows and dancing around while she cleans her house. She says, "It's fun." And that's the whole idea!

Log onto [www.caregiver.com](http://www.caregiver.com) and post a fun workout idea you've tried for other caregivers to try, you might even learn a fun new workout for yourself.

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### CHARGE Syndrome: An Overview

Perkins school for the Blind in the USA has useful resources available. Two webcasts have recently been added specifically relating to CHARGE Syndrome.

<http://www.perkins.org/resources/webcasts/>

CHARGE Syndrome: An Overview

By Pam Ryan

In this webcast, Pamela Ryan, Perkins School Psychologist, offers an over-

view of the characteristic features of CHARGE Syndrome and discusses the very diverse ways these features may manifest themselves in children.

She talks about some of the early medical complications that many children face and how these issues affect development and learning.

CHARGE Syndrome: The Impact on Communication and Learning By Martha Majors. This very insightful

webcast explains the physical, sensory and neurological issues shared by many children with CHARGE and how these issues can affect their success in school. Martha Majors, who has served many children with CHARGE in the Deafblind Program at Perkins, offers guidance for educators in developing an effective educational program that will improve the emotional wellbeing and success in learning for students with this syndrome.

### Call for Presentations 2011

Attention Professionals and Parents:

You are receiving this email because of past participation - or interest expressed in - the CHARGE Syndrome Foundation, Inc.'s (U.S.A.) biennial conference for families and professionals. Attached are the Call for Presentations and Proposal Form files for the 10th International CHARGE Syndrome Conference, July 29-31, 2011 in Orlando, Flor-

ida. If you know of an individual or organization which has not received this, and is interested in presenting, please forward to them. Please note the deadline for submission is November 1, 2010 with notification to presenters in January of 2011.

If you are involved in an organization which publishes a newsletter, please mention our Call for Presentations and include my contact infor-

mation: Marilyn Ogan, 2011 CHARGE Conference Program Chair, [marilyn@chargesyndrome.org](mailto:marilyn@chargesyndrome.org). Please direct any questions regarding program to my attention.

I eagerly await responses and proposals that will make this conference program the best ever!

Sincerely,  
Marilyn Ogan

### RIDBC Internet Resources

RIDBC has produced a Resource booklet called Internet Resources - a select guide for RIDBC parents. This useful booklet has a wealth of

websites relevant to parents of vision and/or hearing impaired children.

Copies can be obtained by

emailing:  
[julie.thorndyke@ridbc.org.au](mailto:julie.thorndyke@ridbc.org.au)

## Families in CHARGE

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### WE ARE GOING TO PERTH

Hi everyone,

Well there is only 156 days till our conference and if you are anything like Simon and I you have been counting down since the announcement in Christchurch in October 2008!!

We were both so excited. Yay, Natalie will be a bit older and hopefully stronger and we couldn't remember the last time we had any sort of holiday. Certainly not since Natalie had been born and our wheels had been buckled a bit! We got so much out of the last conference with the networking, information but most of all having a weekend where we felt like any other "average normal family" and so we just knew we HAD TO GO! So we started to think and brain storm and plan. What could we do to ensure we were able to go? Both Natalie and Olivia (love them to bits) are a handful at times, Simon and I both work full time and are also in the process STILL, of working through our leaky home syndrome so we knew that we would not be able to save the money required. We were going to have to do some fundraising for ourselves.

But what??? Selling sausages outside The Warehouse (where everyone gets a bargain) was not my idea of fun and we would probably need to sell them every weekend for 2 years to raise enough money! We needed to think big and I suggested to Simon that if we could hold 1 big event and do it well, it might just get us what we needed to ensure we could all go as a family. Fortunately in my background (or former life), I was a Cabaret Dancer and worked with many entertainers over the years. So I contacted my very dear friend – NZ's own International Hypnotist and Comedian Guy Cater – [www.hypnotist.co.nz](http://www.hypnotist.co.nz) – Guy and his lovely wife Cynthia agreed to put on a show for us called "The Ultimate Comedy Show". We found a venue in the city, organised a liquor license and started to sell tickets. Then 1 of the girls I work with (Mellissa) nominated us on our local radio station "The Breeze" for "Win a Wish". I was called and interviewed live on the radio. "The 2 Robbies" asked me all about Natalie and CHARGE and our fundraiser. Then they

told me they had created an advert which they would run on air for the next 2 weeks leading up to our fundraiser to try to help sell tickets!! WOW what an overwhelming feeling that was. They also wanted to come along on the night and open up the show. So the ad ran it talked a bit about CHARGE Syndrome and a bit about our fundraiser and we were on our way. Friends and family got stuck in with us and helped us out with the organising. We had people on the door and on the bar and in the kitchen helping Simon prepare the supper.

The show was a brilliant success!! We couldn't have asked for a better night. Everyone had a great time and we raised enough money so WE ARE GOING TO PERTH!! So if you really want it like Simon and I do... you CAN have it.. just reach for the stars cause you never know where you'll land and enjoy the ride along the way. Hope to see as many of you as possible in October.

Take Care,

Lisa Kerr

## Autumn 2010

### Stephanie at 8 years

This is Stephanie at 8 years old. She was born with most of the typical CHARGE health problems,



supported by the principal and her teachers (past and present) and two very special TA's, she uses a FM hearing system in the classroom which really helps to hear the teacher clearly. She has lots of friends and enjoys going to school every day.

She is now walking unassisted but still has balance issues and muscle fatigue, but she is determined to be the best that she can be

and her friends give her lots of encouragement.

She has recently competed in the school's cross country carnival at Centennial Park where she ran 2kms with the whole school screaming for her

and cheering her on. She is simply the most amazing person I have ever

met.

by Angela Begas

double aortic arch surgery, laryngo/tracheomalacia,

NG and then G-tube fed due to no swallowing, fundoplication for reflux, CPAP for sleep apnea, delayed gross motor development, bilateral colobomas, profoundly deaf in left ear with no balance at all.

She goes to a mainstream public school and is well



### New Directions for Disability Respite Services in NSW

The paper has been developed with the aim of building a Disability Respite Service system that is more responsive to the individual needs of people with a disability and their carers and families. During the consultation period many detailed submissions were received and comments on a wide range of

areas where ADHC Human Services could improve respite support services

The feedback that has been received has provided invaluable information and has enabled DADHC to shape the final version of this paper to clearly set out the vision for the future provision for respite

services in NSW. This draft has been finalized and endorsed by the minister for aging and Disability service, Hon Paul Lynch MP

Copies of this draft paper can be downloaded from the Web site

[www.adhc.nsw.gov.au](http://www.adhc.nsw.gov.au)

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### Things you didn't know you didn't know

#### ITS MADE FROM FISH OIL

The Magic of WD40 - Interesting...

A lady got up very early one morning and went outside to pickup the Sunday paper, she noticed someone had sprayed red paint all around the sides of the neighbors brand new beige truck. She went over and woke him up and gave him the bad news. He was, of course extremely upset.

And they stood there trying to figure out what could be done about the problem.. They decided there wasn't much recourse but to wait until Monday, since nothing was open. Just then another neighbor came out of his house, surveyed the situation and immediately went to get his WD-40 out and cleaned the red paint off with it. Guess What! It cleaned up that paint without harming the original paint on the truck!

I'm impressed!!

Water Displacement #40. The product began from a search for a rust preventative solvent and degreaser to protect missile parts.

WD-40 was created in 1953 by three technicians at the San Diego Rocket Chemical Company..

Its name comes from the project that was to find a 'water displacement' compound. They were successful with the fortieth formulation, thus WD-40. The Corvair Company bought it in bulk to protect their atlas missile parts.

Ken East (one of the original founders) says there is nothing in WD-40 that would hurt you... IT IS MADE FROM FISH OIL. When you read the "shower door" part, try it. It 's the first thing that has ever cleaned that spotty shower door.

If yours is plastic, it works just as well as glass. It is a miracle! Then try it on your stove top... It is now shinier than it has ever been before .

WD 40 also:

- 1) Protects silver from tarnishing.
- 2) Removes road tar and grime from cars.
- 3) Cleans and lubricates guitar strings.
- 4) Gives floors that "just-

waxed" sheen without making it slippery.

5) Keeps flies off cows.

6) Restores and cleans chalkboards.

7) Removes lipstick stains.

8) Loosens stubborn zippers.

9) Untangles jewellery chains.

10) Removes stains from stainless steel sinks.

11) Removes dirt and grime from the barbecue grill.

12) Keeps ceramic/ terracotta garden pots from oxidizing.

13) Removes tomato stains from clothing..

14) Keeps glass shower doors free of water spots.

15) Camouflages scratches in ceramic and marble floors.

16) Keeps scissors working smoothly.

17) Lubricates noisy door hinges on vehicles and doors in homes

18) It removes black scuff marks from the kitchen floor!

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Open some windows if you have a lot of marks.

19) Bug guts will eat away the finish on your car, removed quickly, with WD-40!

20) Gives a children's play gym slide a shine for a super fast slide.

21) Lubricates gear shift on lawn mowers.

22) Rids kids rocking chairs and swings of squeaky noises.

23) Lubricates tracks in sticking home windows and makes them easier to open.

24) Spraying an umbrella stem makes it easier to open and close.

25) Restores and cleans padded leather dashboards in vehicles, well as vinyl bumpers.

26) Restores and cleans roof racks on vehicles.

27) Lubricates and stops squeaks in electric fans.

28) Lubricates wheel sprockets on tricycles,

wagons, and bicycles for easy handling.

29) Lubricates fan belts on washers and dryers and keeps them running smoothly.

30) Keeps rust from forming on saws and saw blades, and other tools.

31) Removes splattered grease on stove.

32) Keeps bathroom mirror from fogging.

33) Lubricates prosthetic limbs.

34) Keeps pigeons off the balcony (they hate the smell).

35) Removes all traces of duct tape.

36) Folks even spray it on their arms, hands, and knees to relieve arthritis pain

37) Florida 's favourite use 'Cleans and removes love bugs from grills and bumpers.'

38) Protects the Statue of Liberty from the elements.

39) WD-40 attracts fish.

Spray a LITTLE on live bait or lures and you will be catching the big one in no time.

40) Ant bites. It takes the sting away immediately and stops the itch.

41) WD-40 is great for removing crayon from walls. Spray on the mark and wipe with a clean rag.

42) If you've washed and dried a tube of lipstick with a load of laundry, saturate the lipstick spots with WD-40 and presto the lipstick is gone!

43) If you spray WD-40 on the distributor cap, it will displace the moisture and allow the car to start.

Keep a can of WD-40 in your kitchen cabinet. It is good for oven burns or any other type of burn. It takes the burned feeling away and heals with NO scarring. Remember, the basic ingredient is FISH OIL

## Spring 2010 American newsletter

The Spring 2010 American newsletter is now available

through their website. It has an article on a boy

from Melbourne on Page 9.

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### Tedious diatribes about how hard things were

If you are 30, or older, you might think this is hilarious!

When I was a kid, adults used to bore me to tears with their tedious diatribes about how hard things were. When they were growing up; what with walking twenty-five miles to school every morning.... Uphill...

Barefoot.... BOTH ways yadda, yadda, yadda.

And I remember promising myself that when I grew up, there was no way in hell I was going to lay a bunch of crap like that on my kids about how hard

I had it and how easy they've got it!

But now that I'm over the ripe old age of thirty, I can't help but look around and notice the youth of today. You've got it so easy! I mean,

compared to my childhood, you live in a damn Utopia!

And I hate to say it, but you kids today, you don't know how good you've got it!

I mean, when I was a kid we didn't have the Internet. If we wanted to know

something, we had to go to the library and look it up ourselves, in the

card catalog!!

There was no email!! We had to actually write somebody a letter - with a

pen! Then you had to walk all the way across the street and put it in the

mailbox, and it would take like a week to get there! Stamps were 10 cents!

Child Protective Services didn't care if our parents beat us. As a matter of fact, the parents of all my friends also had permission to kick our ass!

Nowhere was safe!

There were no MP3's or Napsters or iTunes! If you wanted to steal music, you had to hitchhike to the record store and shoplift it yourself!

Or you had to wait around all day to tape it off the radio, and the DJ would usually talk over the beginning and @#\*% it all up! There were no CD players! We had tape decks in our car. We'd play our favorite tape and "eject" it when finished, and then the tape would come un-

done rendering it useless. Cause, hey, that's how we rolled, Baby! Dig?

We didn't have fancy crap like Call Waiting! If you were on the phone and somebody else called, they got a busy signal, that's it!

There weren't any freakin' cell phones either. If you left the house, you just didn't make a call or receive one. You actually had to be out of touch with your "friends." OH MY GOD !!! Think of the horror... not being in touch with someone 24/7!!! And then there's TEXTING. Yeah, right.

Please! You kids have no idea how annoying you are.

And we didn't have fancy Caller ID either! When the phone rang, you had no idea who it was! It could be your school, your parents, your boss, your bookie, your drug dealer, the collection agent... you just didn't know!!!

You had to pick it up and take your chances, mister!

We didn't have any fancy PlayStation or Xbox video games with high-resolution 3-D graphics! We had the Atari 2600! With games

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like 'Space Invaders' and 'Asteroids'. Your screen guy was a little square!

You actually had to use your imagination!!! And there were no multiple levels or screens, it was just one screen... Forever! And you could never win. The game just kept getting harder and harder and faster and faster until you died! Just like LIFE!

You had to use a little book called a TV Guide to find out what was on! You were screwed when it came to channel surfing! You had to get off your ass and walk over to the TV to change the channel!!!! NO REMOTES!!! Oh, no, what's the world coming

to!!!!

There was no Cartoon Network either! You could only get cartoons on Saturday Morning. Do you hear what I'm saying? We had to wait ALL WEEK for cartoons, you spoiled little rat-finks!

And not many of us had microwaves. If we wanted to heat something up, we

had to use the stove!  
Imagine that!

And our parents told us to stay outside and play... all day long. Oh, no, no electronics to soothe and comfort. And if you came back inside... you

were doing chores!

And car seats and seat

belts - oh, please! Mom threw you in the back seat

and you hung on. If you were lucky, you got the "safety arm" across the chest at the last moment if she had to stop suddenly, and if your head hit the dashboard, well that was your fault for calling "shotgun" in the first place!

See! That's exactly what I'm talking about! You kids today have got it too easy. You're spoiled rotten! You guys wouldn't have lasted five minutes back in 1980 or any time before!

Regards,

The Over 30 Crowd

## COMPANION CARD

The Australian Government has introduced a COMPANION CARD for all persons with a life long disability who require assistance to attend various activities in the community.

This card entitles the Carer, (can be parent, support worker or anyone who assists the person with a disability) to get out and about in the community

Each state and territory has a different list of supporters of

this card, but such things as Movies, Zoo, council activities, PUBLIC TRANSPORT, and many others entitle to Support Person to gain FREE entry to those activities, listed on the Webb site

The application form and information is available on the FACSHIA Webb site

[www.companioncard.gov.au](http://www.companioncard.gov.au)

The card can only be used when the person with the disability is with the support

person. It contains the person's photo and MUST be shown at all point of entry.

There is comprehensive list STATE by STATE on participating venues listed on the Webb site. Considerable savings can be made and also assist families and carers to enjoy their city.

This is a COMMON-WEALTH initiative and can be used in all states at territories.

## Families in CHARGE

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### ASD type behaviours

A number of our Kids with CHARGE Display ASD type behaviours. This article from Parenting Aspergers may have some useful information in it.

Here's this week's article about Aspergers and Employment Prospects in Text Format ...

Question -

We would be most interested in employment support such as best practices for placement, behavior management on the job, workplace accommodations, coping skills on the job, how to develop a mentoring relationship with co-workers, basically how to place and maintain employment.

Answer -

For a person with Asperger's Syndrome, finding (and keeping) employment can be a very difficult endeavor. It all depends on how well a person is prepared for his field of interest. Choosing a career that focuses on a person's special, or limited, interest will raise the chances of successful employment. Jobs that have a set daily routine are also good options.

Career planning should start early, preferably during the high school years. The high school years are a time of self-discovery. The young person with Asperger's Syndrome can begin to prepare for a job in his field of interest by planning to investigate the following options.

\* Job training-Some companies will train a person who is knowledgeable, yet inexperienced.

\* Technical school-These local schools offer short courses that yield a certificate, and sometimes a diploma, in certain technical skills. Examples are computer fields and auto mechanics.

\* College-More people with Asperger's Syndrome are attending college than ever before. Some stay home and attend a community college, while others go away to four-year institutions.

\* Apprenticeship-Specialized careers can be learned this way.

Although, not as common as other options, finding a position as an apprentice will get you intense training in all aspects of a trade or career.

Since people with Asperger's are usually extremely intelligent, most of the problems lie within the social aspects of employment.

Social communication, understanding body language and other unspoken social cues are necessary in the workplace. Time management and organizational skills are also essential.

Several important therapies can help prepare a person with Asperger's Syndrome for employment. These therapies should actually be incorpo-

rated in the daily schedule while a person is still young and in school. As skills are learned and practiced, they become more natural. Before seeking employment, the following skills should be practiced.

\* Social skills-All areas including, personal space, gestures and cues, facial expressions, and social communication, should be practiced. Social skills classes provide directed practice under the watchful eye of a trained therapist.

\* Behavioral therapy-This therapy is performed under the guidance of a trained behavioral therapist, and includes anger management and general coping skills.

\* Organizational skills-Learning to use visual schedules and lists, calendars, as well as learning time management skills comes about when organizational skills are practiced.

Once a person with Asperger's Syndrome finds employment, he must continue to practice these therapies in order to ensure continued success in his field of interest. Developing a daily routine that incorporates a daily schedule, social skills reminders, and rules to work by will provide the basics for continued employment.

Thanks for reading,  
Dave Angel

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### The Caregiver's Balancing Act

By: Kristine Dwyer, LSW

In the 1960s, TV celebrity Ed Sullivan featured a Chinese talent artist who demonstrated the careful balance and timing of spinning porcelain plates atop thin, wooden sticks. The key was to start spinning a stack of plates one at a time and then dash from plate to plate keeping each one in motion to prevent them from crashing to the floor. Viewers watched in amazement as plates slowed their pace and began to wobble precariously, yet miraculously the man was able to reach each plate at the last second just before it tipped. The artist then ended the performance by quickly gathering up each teetering plate into a neat pile without a single disaster.

Caregiving today can often be compared to this entertaining yet realistic experience. Balancing the multiple roles and responsibilities of our lives is a constant challenge. Each plate may represent a different part of our lives as we work tirelessly to maintain motion and balance. They can symbolize personal needs, marriage, family, career, friendships, health issues, finances, social and physical activities. These are the plates of everyday life that one can expect to spin. Then when one becomes a caregiver, several more plates are added such as personal and medical care, transportation, supervision of safety needs, emotional support, companionship, financial oversight and

decision-making for the well being of a loved one. Add in the weight of a few unexpected events such as sudden illness, job loss, or a divorce and it can be very difficult to keep all of the plates spinning in unison without a calamity.

Although we want to avoid losing our momentum, a sudden crash of a plate or an unexpected personal emergency can be a time of awakening. It can also be a call to reprioritize as we evaluate the results of a fallen plate. One may ask, Should I keep spinning these plates alone or ask for help? Should I remove a plate before it falls, or perhaps set one or two aside to focus on fewer plates for awhile? Keeping an eye on our spinning plates is important to assess our capabilities and the challenges we are facing.

If we live in a continuous scramble between the plates, we may lose our focus on what is truly important and jeopardize our own health and safety, not to mention the well being of those we care about.

Caregiving for a loved one may last for months or many years. In addition, the number of plates may change or be replaced as life unfolds and we strive for a healthy balance. Whether you decide to keep all of the plates spinning at once or set a few aside, caregiving support can be received in many ways: attend a support group or personal counseling sessions to gain a perspective

of the caregiving situation, build a support network to include family, friends, medical personnel, clergy and a social worker/care manager, accept assistance with personal care needs from family members and friends to lighten the load, hire private help even a few hours a week for household and chore services, accept respite care opportunities to allow a break from caregiving and find ways to renew one's own body, mind and spirit.

We may not all be as talented as the Chinese balance artist, but we can use our own inner resources and the help from others to attain steadiness in our lives. Providing care to someone in need may be one of the most important roles one will ever fill in a lifetime, yet it does not have to be done alone. The first step is to recognize that we are spinning too many plates or that the plates are teetering out of control. The second step is to ask for help. This is a sign of strength, not weakness, and is the surest way to keep all of the facets of our lives in careful balance.

Kristine Dwyer is a Caregiver Consultant and Licensed Social Worker with Carlton County Public Health and Human Services in Cloquet, Minnesota. She is also a past and current caregiver for family members.

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## Improving the quality of life for children and adults with CHARGE Syndrome

The CHARGE Syndrome Association of Australasia is a not-for-profit organisation committed to improving the health and welfare of children and adults with CHARGE Syndrome. The Association supports families in Australia and New Zealand to enable children and adults with CHARGE Syndrome to reach their full potential.

Since the formation of the parent support group in Australia, 1994, conferences have been held every 2 years. A newsletter is produced, fundraising activities occur and planning for future needs of these children and young adults is a major consideration.

Families of newly diagnosed children with CHARGE are provided with an information package on request, and parent and professional representatives are available to discuss CHARGE with any interested persons.

Interested medical and educational professionals have involved themselves in gaining data about children in Australia and New Zealand. Such professionals also keep abreast with current developments locally and internationally.

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### Child care in China

Our family visited China for three months. The following was the email that I sent to our family about the problem that we had with the first child care centre that we enrolled Raphael into.



Raphael's first child care. We looked at a few of the nearby child care centres and decided that this was the best one. When we went there we met the carers ("teachers" in China) and the office staff and they met Raphael. They told us what the next step would be and they told us that we needed to go and get a blood test taken. After having this done we brought him in and paid the money then we met the principal. She took one look at Raphael's hearing aid and immediately said that they

could not accept Raphael in the centre because of his disability. To reduce the length of what is a long story she eventually recognised that they had already caused Raphael to have a blood test for acceptance and so she accepted him. The story does not end there though.

The following day when we turned up she met Annie and said that she had found out from the teachers that Raphael was still wearing nappies (we had told the teacher about this when we came in previously) and that this was another reason that they could not accept him. She said that they would be happy to trial him in the centre for two days to see how it went. So we left him there. That evening when we went to pick him up, the principal said that one of the teachers had handed in a letter of resignation because of Raphael and if we could convince her to stay then Raphael could stay.

The next day Annie went to talk to the teacher who had written the letter of resignation and she said that she had not resigned and that there was no problem as far as she was concerned. In fact the same was for all 4 teachers of

Raphael's class and the medical officer in the centre said that Raphael was fitting in fine and seemed to be very intelligent, already knowing what was going on despite the language gap (hmm, something fishy is going on with that principal). The end result was that Raphael was expelled despite us meeting every requirement and even offering a significant amount of more money to help the centre meet the additional costs of looking after him (which there were none). We did not want to push the matter any further because it was clearly not a matter of finding solutions to problems but rather some kind of phobia. If the principal does not want Raphael in the centre then we don't want Raphael there either. So we looked for a new child care centre (more on this later).

Later the medical officer called us saying how bad she felt about Raphael being rejected. She was very sweet and kindly offered her time to help us push the matter further or find another centre but by that stage we had already found another child care centre.

Paul Bartlett