



VCFS & 22q11 Magazine

July 2010

President's Report

Well how the time flies. As I prepare for my trip to the VCFSEF conference in Salt Lake City this month I am noticing just how much our foundation has done and will continue to do. I have been in consultation with Dr Linda Campbell recently. Linda is now the VCFSEF Regional Director for Australasia. Linda has taken over the role from Stephen Russell who put in many years on the VCFSEF board and was the key person in getting the VCFS Clinic at the Mater Hospital in Brisbane.

I would like to wish Linda well in this new position and hope to work with her closely for the benefit of all affected by VCFS in Australasia.

The committee has been working hard on getting the 2010 Conference speakers organized. I am looking forward to sharing all the information we gather at the VCFS conference in Salt Lake City with you at the conference.

The conference is also our AGM. If you would like to volunteer to be on the board please let us know by completing the nomination form in this newsletter. Volunteering can be a rewarding and fulfilling experience. It also gives you the opportunity to put forward your ideas for the future of VCFS in Australia. The current committee has put in so much time and effort and it would be great if we could get more volunteers to assist. We do have a couple of board members stepping down this year due to other commitments. I would like to thank them for their passion and dedication to the VCFS & 22q11 Foundation.

The conference on the 22nd August is also the start of our VCFS Awareness Week. This year we have two different community service announcements being aired on free TV across Australia during August. Thanks to Lucy who arranged Lisa Wilkinson of the Today show to support VCFS and star in one of the commercials. Having someone so prominent will hopefully raise our profile and awareness. I would encourage as many of you to get involved in local community initiatives to raise awareness. Pink and Blue day is Friday 27th August. Last year we had many schools getting involved by dressing in pink and blue for a gold coin donation. Hopefully we can do it again this year. Many of our members held morning teas and lunches to raise awareness. I am also pleased to announce some international groups have also joined us by having awareness weeks approved by their governments. One day maybe we will have an international awareness week!

The website will be updated with ideas for awareness campaigns shortly.

I look forward to seeing many of you at our conference.

Maria Kamper

In this issue

Family Story

President's report

Research from

Around the Globe

Poets Corner

What's On

Contact us

VCFS & 22q11 Foundation Calendar

- **General Meeting**
1st August 2010
- **Conference and**
AGM 22nd August
2010

**This is your reminder
that membership to the
VCFS & 22q11
Foundation is now due.**

**If you haven't recently
joined or renewed, please
use the membership form
included in this issue or
visit our website.**

www.vcfsfa.org.au

**If you are unsure of your
membership status please
send us an email.**

membership@vcfsfa.org.au

VCFS & 22q11 Foundation Inc

Families & Professionals supporting those affected by
VCFS & deletion 22q11
Registered Charity CFN 13849
ABN 22 379 450 116

www.vcfsfa.org.au

Michael's Story



My name is Alta Jones. I am 37 years old and I have a son Michael.

I would like to share my story with you the readers in the hope that more is done to help our children to cope with life out there.

Michael was born on the 2nd of April 1994 in Liverpool Hospital with quite a few problems, some visible and others not.

He had a growth on the right lower side of his jaw; it was found to be a Bronchial cyst, which was restricting his airways for the first month. We had fed him with a tube, as any other feeding would cause him to stop breathing, which he did twice right at birth. You can imagine how heartbreaking that is for a parent.

As Michael started to grow, we discovered that his calcium and white T-cell counts were very low. After spending 14 days in the baby intensive care unit he started to improve and was moved to a normal ward.

Now it was time to concentrate on his Bilateral Talipes and get that that sorted, they slowly stretched his tendons on his ankles in readiness for release later if necessary. We also discovered during weekly checkups that his kidneys didn't seem to be working correctly. Upon further investigation it was discovered that Michael's left kidneys, had a duplicate systems, a single on the right so in layman's terms Michael's kidneys had three ureters so yet again it was off to surgery for the second time in his little life to fix things up.

In the process of getting things fixed, my pediatrician suggested that we have extensive blood tests done to find out if any or all these symptoms were linked in any way.

At age of three we found out that Michael had VCFS, we were lucky as our geneticist was at the time studying VCFS and was able to give me some information to read as well as some web sites to look at that may help me.

So to sum up Michael's story is that after 5 major operations, 9 heat seizures, countless doctors and a great leap of faith that we can manage.

For the future we had a fantastic support team behind us to help whenever or whatever is required, my parents are there to lend a hand or a shoulder to lean on.

We do have our ups and downs but look on the bright side and you will be rewarded. Michael has problems at school and he is, trying to cope in High School. We hope and pray for him that he get some education to help him through life.

Thanking everyone who takes time to read my story and all I can say is that never give up as there is always help all you need, just ask for it.

Kind Regards to all Parents who have VCFS children.

Do you like reading our family stories?

Supply is drying up fast. Please send us your story and photo so we can continue to publish them in our magazine. Send your story to

editor@vcfsfa.org.au

Become a Volunteer

Volunteering can be a rewarding job. The foundation can only continue to raise awareness with its volunteers.

Contact the president at

president@vcfsfa.org.au

To accomplish great things, we must not only act, but also dream, not only plan, but also believe.

Anatole France

“The hardest arithmetic to master is that which enables us to count our blessings”- Eric Hoffer



Media Release

New strategy to improve and expand services for people with a disability

Release Date: 30 June 2010

Services for people with a disability are expected to be greatly enhanced after adoption of the recommendations in a major report which sets a clear direction for the not-for-profit disability sector in NSW.

The report, Directions for Industry Development, released by the NSW Government and National Disability Services (NDS) today details strategies and actions to be taken over the next five years.

The Minister for Disability Services, Peter Primrose, said that the report focused on placing people with a disability, their families and carers firmly at the centre of service delivery.

He said that the report included a range of activities that the Keneally Government would look to pursue, either directly through Ageing, Disability and Home Care (ADHC), or through other areas of government.

“There are opportunities for true innovation in this report, particularly in building new partnerships with mainstream services, so that people with a disability get the same access to basic services that we all enjoy,” Mr Primrose said.

Mr Primrose said that the non-government sector played an essential role in partnership with ADHC to support people with a disability and their families in improving quality of life.

“Governments are paying increasing attention to capacity building in the non-government sector,” he said.

“A strong, robust and effective non-government sector is able to build the capacity of the community and able to develop ‘social capital’ for the community’s benefit.”

“The need for true and effective partnerships between the community sector and Government cannot be overstated.

The NSW Government announced the \$17 million Industry Development Fund (IDF) in June 2009 to be used by the disability sector to build the capacity and sustainability of services.

NDS State Manager Patrick Maher said that the report set out a strategic focus for the sector.

“It moves us beyond a funding relationship into a partnership with the NSW Government which provides a powerful mechanism to achieve quality outcomes,” Mr Primrose said.

“Focusing on industry development will further support the transition to a more integrated, efficient, innovative, robust and responsive service system to achieve quality outcomes for people with a disability and their families.”

Mr Maher said that the non-government sector was committed to making efficient use of government funds to maximise outcomes on behalf of people with a disability.

The Directions for Industry Development report followed extensive consultation with stakeholders including advocates, peak organisations, service providers and policy makers and will guide the utilisation of the Industry Development Fund.

An implementation group including representatives from ADHC, NDS, peak organisations and service providers will provide oversight over the development of detailed project plans and advise the IDF Governance Board on industry development projects and strands of reform that will achieve the identified outcomes.

Have your say about disability services

***Stronger Together: A new direction for disability services in NSW 2006-2016* is the NSW Government’s 10 year plan for disability services.**

During June and July 2010 the Minister for Disability Services, Peter Primrose is hosting a series of consultations across the state to inform the next phase of ***Stronger Together***.

A [consultation paper](#) has been developed which reports on what *Stronger Together* has achieved so far and which asks some key questions about planning, modelling and service delivery in NSW.

The NSW Government invites members of the community, who have an interest in improving disability services in NSW, to have input into the planning process by making a submission.

You can make a submission by:

- Responding to some of the key questions raised in the consultation paper [online](#)
- Emailing your comments to strongertogether@dadhc.nsw.gov.au or
- Posting written comments to:

Stronger Together consultation feedback
Ageing, Disability and Home Care
Level 5, 83 Clarence Street
Sydney NSW 2000

Your submission must be received by 5.00pm 19 July 2010.



Do you have a child with a disability living at home? We want to hear from you

Do services work together to help you?

Are you getting help to support your child to live at home?

We are very interested to hear from families about:

Specialist disability services including:

- information about disability services and being taken on to receive services
- intensive family support and other family support
- respite
- early intervention
- therapy
- case management
- transition support services (transition to school, from school to work, and when leaving care to adult disability services.)
- support for carers
- physical aids and equipment
- the way specialist services work together and link to mainstream services for families and children.

Services for families in the community such as:

- child care, out-of-school hours care and vacation care
- pre-school and primary and secondary school
- health services
- public transport
- sport and recreation.

It is important that children with a disability and their families get the help they need. We will let government know what families say about the support and services they need.

Share Your Views

You can share your views in person, by telephone or by email. To participate please contact:

Christine Flynn, Project Manager Telephone: (02) 9265 0410 email: cflynn@ombo.nsw.gov.au

Linda Blue, Project Officer Telephone: (02) 9286 0950 email: lblue@ombo.nsw.gov.au

Or phone toll free: 1800 45 1524

We will be talking to families between May & August 2010

Privacy and confidentiality

What you tell us will be kept confidential by our office. Your personal information, for example, your name, will not be used in the report. Individual services will not be named – we are looking at the overall system.

Independence: The NSW Ombudsman is independent of government and community and disability services.

“A mixture of empathy and brainstorming can move mountains”- Hazel Hawke



Learning Difficulties Coalition NSW Inc
For Parents, Teachers & Health Professionals

Reading Difficulties: Research and Treatment

Presenter: Dr Genevieve McArthur

**Australian Research Fellow from the Macquarie Centre
for Cognitive Science (Macquarie University)**

Tuesday 14 September 2010, Parramatta

Venue: Parramatta Leagues Club 13-15 O'Connell Street, Parramatta

Time: Registration 9.30am, Presentation 10.00am - 12.00pm (approx. Including question time)

Parking: Free Onsite Parking Available

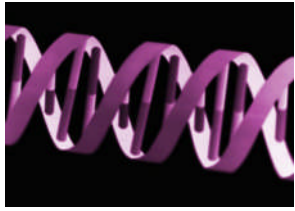
Cost: (Tea/Coffee included) \$ 25 LDC member \$ 55 non LDC member \$ 50 Seminar Entry & New Membership

In her presentation, she will discuss the definition of developmental dyslexia (i.e. reading difficulty) and how it can be diagnosed. She will discuss theories about what causes developmental dyslexia, outline commercial treatments that have been triggered by these theories, and the scientific evidence behind these treatments. Additionally, she will provide a step-by-step guide that will help teachers, parents and educational professionals assess the existing evidence for new treatments for developmental dyslexia. This guide will help us to make more informed decisions about the best forms of treatment for children with developmental dyslexia.

REGISTER ONLINE at www.ldc.org.au

As seats are limited, **REGISTRATION AND PAYMENT MUST** be received by Tuesday 7 September

Refund of fees, less 30% administration, will be available up to 14 days prior to conference commencement.
No cancellations accepted later than 14 days to conference. Substitute delegates welcomed at no extra charge.



Research from Around the Globe

Disruption in Brain Connection Linked to Genetic Defect in Schizophrenia

In what may provide the most compelling evidence to date, researchers at Columbia University Medical Center have illuminated how a genetic variant may lead to schizophrenia by causing a disruption in communication between the hippocampus and prefrontal cortex regions of the brain, areas believed to be responsible for carrying out working memory.

This discovery coincides with the 15th anniversary of the first identification of the link between schizophrenia and a genetic mutation -- a microdeletion on human chromosome 22 -- known as 22q11 deletion, by Columbia Psychiatry researcher Maria Karayiorgou, M.D., a coauthor on the research. Previous studies have shown that approximately 30 percent of patients with this deletion will go on to develop schizophrenia.

"We know that this genetic deficit predisposes us to schizophrenia, and now we have identified a clear pathophysiological mechanism of how this deletion confers this risk for schizophrenia," said Dr. Karayiorgou. Dr. Karayiorgou discovered the link between the 22q11 mutation and schizophrenia in 1995. Since then, Dr. Karayiorgou and Joseph A. Gogos, M.D., Ph.D., a senior author on the research, have established and pursued research focusing on the neurobiology of this mutation.

Though schizophrenia is best known for its delusions and hallucinations, it is the disease's impact on such cognitive abilities like working memory -- a key element of executive functioning -- that best predict how well a person will function in society.

Using a mouse model with the 22q11 deletion, senior authors Joshua Gordon, M.D., Ph.D., and Joseph A. Gogos, M.D., Ph.D., and their teams, recorded the neural activity of the mice while they performed a cognitive task of working memory, and found that their performance was either completely disrupted, or was impaired, compared to that of the healthy mice.

(Dr. Karayiorgou is professor of psychiatry, Dr. Gogos is associate professor of physiology and neuroscience, and Dr. Gordon is assistant professor of psychiatry at Columbia University Medical Center).

In healthy mice, the hippocampus sends spatial information to the prefrontal cortex, but in the mouse model of the 22q11 mutation there is a breakdown in the connection and this communication is either weakened or fails completely.

As part of the cognitive trial, the mice were tested as they navigated a t-shaped maze. In order to successfully complete the task, the mice had to recall the direction in which they travelled, and then choose to go in the opposite direction to receive their next reward. While the healthy mice easily learned the task, mice carrying the schizophrenia mutation took longer to master it, demonstrating a behavioural deficit of the task in the mouse model of schizophrenia.

"We found that successful completion of the task in our healthy mice required the two regions of the brain -- the hippocampus and the prefrontal cortex -- to work together, and in our mouse model, the information transfer was less efficient, or was unable to take place at all," said Dr. Gordon.

In addition, the researchers reported that they were able to show the extent of the deficit in individual mice.

"There was a variation in how much of a deficit they showed, and that correlated with the degree of the behavioural deficit, so that for individual mice that have less communication between these structures, there was more of a behavioural deficit," said Torfi Sigurdsson, Ph.D., a postdoctoral research scientist in Dr. Gordon's laboratory at Columbia Psychiatry and a co-author on the paper.

Recent human imaging studies have suggested the possibility that there may be abnormalities in the functional connectivity between the hippocampus and prefrontal cortex in schizophrenia, however, it remained unclear how such findings related to a cause of the disease, like that of a genetic risk variant, or if they were the result of the disease itself or medications used.

"Here we are really at the level of the individual cells, so our findings extend beyond patient studies by showing how disrupted connectivity can arise at the level of single neurons, as a result of a genetic risk variant," said Dr. Sigurdsson.

Another strength of the study, according to the researchers, is that the communication can be measured directly between the two regions.

"It unequivocally establishes a deficit in that communication in a way that the early studies could not -- not only because we can isolate the genetics of the disease, but we can also measure the connectivity between these structures directly," said Dr. Gordon.

"The 22q11 deletion mouse model allows us to explore how these mutations alter brain function and the abnormal behavior that we see in schizophrenia patients. This is exactly what our study and our research program on 22q11, in general, has accomplished," said Dr. Gogos.

"We now know that one of the consequences of that deletion is to disrupt functional communication between these two brain regions, and we have evidence from the study that the disruption actually has an impact on a cognitive behavior that is disrupted in patients, so it gives us a really strong indication of how the deletion can contribute to the development of schizophrenia," he added. "It is possible that similar abnormalities in functional connectivity may also account for other symptoms of the disease, and can be used to better assess treatment response, and, most importantly, to develop new medications.".....continued

Continued

Next, the researchers plan to test the structural links between the hippocampus and prefrontal cortex, since it appears likely that synchrony between these two regions is mediated through anatomical connections. The researchers will examine how the anatomical and synaptic properties of these connections change in this mouse model and will aim to identify the genes that account for this change. Authors of the *Nature* study are Torfi Sigurdsson, Kimberly L. Stark, Maria Karayiorgou, Joseph A. Gogos and Joshua A. Gordon. This study was supported in part by the Simons Foundation, the National Institute of Mental Health (NIMH), and the Lieber Center of Schizophrenia Research and Treatment.

Contrary to popular belief, schizophrenia is not a split personality; it is a chronic, severe, and disabling brain disorder that affects just over one percent of the adult population and is characterized by loss of contact with reality (psychosis), hallucinations (usually, hearing voices), firmly held false beliefs (delusions), abnormal thinking, a restricted range of emotions (flattened affect) or inappropriate and disorganized behavior, social withdrawal, and diminished motivation.

The disease often strikes in the early adult years, and although many individuals experience some recovery, many others experience substantial and lifelong disability. People with schizophrenia often have problems functioning in society and in relationships and are over-represented on disability rolls and among the homeless and imprisoned.

What precisely causes schizophrenia is not known, but current research suggests a combination of hereditary and environmental factors. Fundamentally, however, it is a biologic problem (involving changes in the brain), not one caused by poor parenting or a mentally unhealthy environment.

More Research

Oral health and 22q11 deletion syndrome: thoughts and experiences from the parents' perspectives.

ABSTRACT

International Journal of Paediatric Dentistry 2010; 20: 283–292

Background. 22q11 deletion syndrome (22q11DS) is one of the most common multiple anomaly syndromes, and many dentists are likely to meet patients with the syndrome. Odontological research has focused on describing and analysing conditions/concepts based on the current state of knowledge within the dental profession. Yet, these research topics are not necessarily the most important issues for the patients.

Aims. To explore and describe, by use of Grounded theory, parents' experiences of oral health issues and needs for dental care in their children with 22q11DS.

Design. Twelve parents from different regions in Sweden were interviewed. Analyses were carried out according to Grounded theory.

Results. Parents recognised good oral health as important for the wellbeing of their children. Oral health was a concern and the parents described the fight for this as struggling in vain for good oral health in their child.

Conclusions. Parents not only described their children's oral health as important but also hard to gain. Thus, it is important that all patients with disabilities, regardless of whether there is a defined medical diagnosis or not, are identified and well taken care of in the dental care system.

22q11.2 Deletion Syndrome: Are Motor Deficits More Than Expected for IQ Level?

Nancy J. Roizen, MD, Anne M. Higgins, RN, FNP, MAb, Kevin M. Antshel, PhDa, Wanda Fremont, MDa, Robert Shprintzen, PhDb, Wendy R. Kates, PhDc

Published online 21 June 2010.

Objective

To examine motor function in children with 22q11.2 deletion syndrome (22q11.2) and a Full Scale IQ (FSIQ) comparable control group.

Study design

This study was part of a prospective study of neuropsychological function in children 9 to 15 years of age with 22q11.2 and community control subjects and included children from these two populations with comparable FSIQs.

Results

Verbal IQs on the WISC-R for 40 children with 22q11.2 (88.4) and 24 community control subjects (87.2) were not different ($P = .563$). However, the performance IQs were (22q11.2; 81.1 vs community controls; 89.3; $P < .001$). On the Visual Motor Inventory, there was no difference between the standard scores of the two groups (22q11.2; 93.0 vs community control subjects; 98.1; $P = .336$) but on the motor coordination part of the Visual Motor Inventory, the scores of the 22q11.2 deletion syndrome group were lower (77.2 vs 89.3; $P = .002$). On the general neurologic examination ($P = .906$), the tone examination ($P = .705$), and the ball skills part of the Motor Battery, ($P = .378$), there were no differences. However, on the axial stability part of the Motor Battery, the children with 22q11.2 exhibited less good balance ($P = .026$).

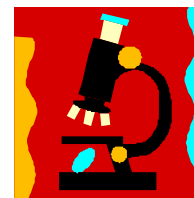
Conclusions

School-aged children with 22q11.2 have specific motor deficits in axial stability and graphomotor skills.

Research Continued

Caries-related saliva properties in individuals with 22q11 deletion syndrome

Gunilla Klingberg, DDS, PhD Peter Lingström, DDS, PhD, Sólveig Óskarsdóttir, MD, PhD, Vanda Friman, MD, PhD, Eva Bohman, DDS, Anette Carlén, PhD



Received 18 April 2006; received in revised form 4 September 2006; accepted 25 September 2006. published online 20 January 2007.

Objectives

The aims were to compare saliva secretion rate, buffer capacity, cariogenic bacteria, total protein, IgA, and electrolytes between patients with 22q11 deletion syndrome (22q11DS) and control subjects and to study correlations between saliva and serum levels of IgA and electrolytes in 22q11DS patients.

Study design

Twenty-nine consecutive 22q11DS patients (mean age 12.6 years) and matched healthy control subjects were clinically examined, and stimulated saliva samples were collected.

Results

Patients with 22q11DS had impaired salivary secretion rate ($P < .01$) and buffer capacity ($P < .05$), higher numbers of cariogenic bacteria ($P < .01$), increased saliva protein concentrations ($P < .001$), and reduced output of electrolytes ($P < .001$ – $.05$) compared with control subjects. A correlation between concentration in serum and saliva was found only for IgA ($r = .622$; $P < .01$).

Conclusions

Different salivary components were affected in patients with 22q11DS, which may explain the increased caries risk seen in these patients.



Dentistry Of Future? Gene Responsible For Formation Of Enamel Discovered

ScienceDaily (Mar. 3, 2009) — A team of researchers lead by Professor Dr Thimios Mitsiadis at the University of Zurich, Switzerland, has identified a gene responsible for the formation of enamel, which is the key component of the teeth. The experiments were accomplished in mice carrying a deletion of the transcription factor Tbx1, a gene that plays a principal role in several human malformations (heart, thymus, parathyroid, face, and teeth) associated to the DiGeorge syndrome.

"Subjects afflicted by DiGeorge syndrome exhibit teeth with enamel defects. We have demonstrated that a direct link between impaired Tbx1 function and enamel defects exists. Enamel forms via the mineralization of specific enamel proteins that are secreted by dental epithelial cells called ameloblasts. Our results clearly show that teeth of Tbx1 null mice lacked enamel and ameloblasts," explains Prof Mitsiadis.

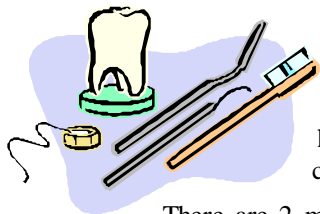
These findings, just published in *Development Biology*, represent a major contribution to the understanding of the production of enamel, the "hardest organic tissue" found in nature.

An American group of researchers from the University of Oregon have also shown a relationship between another transcription factor (Ctip2) and the production of enamel, but in the words of Prof Mitsiadis "our investigations better demonstrate the lack of enamel in teeth. Because of the early lethality of the Tbx1 mutant mice, we have used long-term culture techniques that allow the unharmed growth of teeth until their full maturity. No such studies were performed from our American colleagues."

Could dental treatment benefit in the future from this revolutionary study? The answer is definitively "yes." "The understanding of the genetic code controlling tooth development and repair will permit us to imagine and generate new products and replacement tissues for injured and unhealthy teeth. However the requirements for functional tooth repair and/or formation are complex. Yet, a single approach has not allowed an effective clinical therapy," says Prof Mitsiadis.

Is it possible to use dental stem cells to stimulate the growth of new enamel? This represents the biggest challenge in the discipline of tooth engineering. "Our results show that Tbx1 is involved in the maintenance of dental epithelial stem cells that are responsible for ameloblast formation. In some cases of genetic tooth anomalies, regeneration and repair of teeth could be treated by stem cells. Aggregates of dental stem cells could be used in the future for local transplantation in the dental tissues," explains Prof Mitsiadis

"Even the best quality leather has flaws"- P.K Shaw



Oral Health Issues

Children affected with a 22q11.2 deletion may display certain dental characteristics such as higher number of cavities or poor quality teeth, which may decay quickly. Gastric reflux can contribute to the deterioration of the teeth.

There are 2 main diseases, which are preventable - Gum Disease and Tooth Decay. By preventing these diseases needless suffering and threat to general health is avoided. Children with a 22q11.2 deletion can be more prone to disease because of:

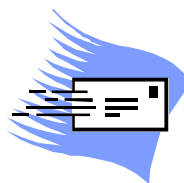
- Poor quality teeth that may decay more easily;
- Difficulty with feeding - i.e. eating smaller amounts but more frequently; Gastric reflux.

Many children with the deletion also require medication and/or calorie supplements and some of these have a high sugar content. This magnifies the need for dental care to protect the teeth and encourage good long-term oral hygiene habits.

For children with heart defects, decayed teeth or inflamed gums also increases the risk of getting a disease of the heart called "infective endocarditis" which is an infection of the inner lining of the heart.



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Working Carers' Gateway

Carers of all ages juggle many responsibilities while having to work either full or part time. This can be a real challenge so you might like to check the useful information on this new website. There is a free monthly newsletter with reports, tips and humour, and information.

Check it out at www.workingcarers.org.au

We would
accomplish
many more
things if we did
not think of them
as impossible.

What's On



VCFS & 22q11 Foundation

General Meeting 1st August 2010 10am

Childrens Hospital Westmead

RSVP: Maria Kamper Ph: 9958 2578 president@vcfsfa.org.au

Conference and AGM 22nd August 2010 Childrens Hospital Westmead RSVP Maria

Learning Links

July 19 and 26 Working with families who are grieving- issues surrounding diagnosis of a disability in children Time 6pm-9pm Cost LLMembers\$121, nonLL members \$131, LLparent members \$69 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

July 29 Positive practices in the classroom for children with ADHD Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

August 3 Total communication- for children who have difficulty following directions and coping with change Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

August 20 Teaching children with disabilities about sex and relationships. Time 10am- 2pm Cost LLMembers\$80, nonLL members \$85, LLparent members \$44 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

September 1 and 8 Working with families who are grieving- issues surrounding diagnosis of a disability in children Time 6pm-9pm Cost LLMembers\$121, nonLL members \$131, LLparent members \$69 Venue: Learning Links, 43 Reservoir Rd, Mt Pritchard. Registrations: Dana (02) 8568 8200

September 6 **ADHD in the early years- understanding and responding** Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue Mt Sinai College, 6 Runic Lane, Maroubra Registrations: Dana (02) 8568 8200

For more information and online booking as well as other topics go to www.learninglinks.com.au

Learning Difficulties Coalition (LDC)

September 14 Reading Difficulties: Research and Treatment Parramatta Leagues Club 13-15 O'Connell St Parramatta Registration 930am Seminar 10.00 – 12.00pm. Cost \$25LDC Member, \$55Non Member, \$50Entry+new membership Book online www ldc.org.au RSVP Tuesday 7th September 2010

Heart Kids

Regular Events:

Westmead Children's Hospital – Coffee Mornings

1st Tuesday and 3rd Thursday each month. Please contact Kim on 0406 420 627 or 9294 0800 for further details.

Sydney Children's Hospital Randwick – Coffee Morning Contact Karen on 0406 424 620 or 9294 0800.

August 14th HeartKids Tiny Tickers Ball 2010 Time 7pm- 1230am The Hilton Hotel 488 George St Sydney Cost \$160 pp members, \$190pp non members. Includes 3 course meal and drinks. RSVP 1st August 2010 Dawn Everingham Ph 0420364125 Fax 02 9834 6841 or email dawn.everingham@heartkids.org.au

September 11th The Tiny Tickers Ball- Orange at the Orange Ex Services Club. Tickets \$90pp. More info call Mardi Aplin 0416112885 or email lifestudion@bigpond.com

November 28th Sydney Christmas Party Olympic Park Homebush, Badu Twin Shade Sales site. RSVP Karen Sherlock 0406424620 or email Karen.sherlock@heartkids.org.au

CleftPals NSW

Morning teas If you are interested please email cleftpalsnsw@gmail.com

VCFSEF

July 16- 18 2010, The 17th Annual International Scientific Meeting, Salt Lake City, Utah USA.

For more information and online registration go to www.vcfsef.org

Family Advocacy

Wollongong 27 July, Burwood 28 July, Bankstown 29 July, Penrith 30 July, Hornsby 11 August Gosford 12 August Newcastle 13 August

Lets Get Started -Getting Ready for School and Life. Registration 10.45am Workshop 11.15am-2.15pm

Information Sessions- Believing in them Supporting big dreams Building bright futures 0930am- 10.45am

For more information about the workshop, venue details and to register, phone (02) 9869 0866 or 1800 620 588 (free call for NSW non metro callers)

August 9th In Control Australia presents Supported Living- Creating a home with self directed support.

9.30am-3.00pm Parliament House Theatre Macquarie St Sydney. RSVP 1st August Cost \$60 professionals or \$20 for people with a disability and families. Register online at www.family-advocacy.com and click on In-Control button on home page.

August 10th Practicalities of Supported Living 9.30am-2.30pm Ryde Eastwood Leagues Club 117 Ryesdale Rd West Ryde. RSVP 3 August 2010. Register and pay online at www.family-advocacy.com and click on Practicalities of supported living link on home page

Addults with ADHD (NSW) Inc

QUARTERLY AWARENESS AFTERNOONS for 2010 Saturdays 2.00pm to 4.30pm:

SUPPORT FOR PARTNERS AND PARENTS OF ADULTS WITH ADHD

Quarterly Luncheons on the last Sunday – 12 noon-2pm

June 27, September 26, November 28

Venue: Macquarie Hospital 3/51 Wicks Rd Nth Ryde

Email or phone the office 02 9889 5977 / 0416 111 036



VCFS & 22q11 Foundation

2010 Conference
Children's Hospital Westmead
From 9am

Free to members & their guests (membership is \$20) Lunch Included
Visit www.vcfsfa.org.au/pages/side-menu/membership.php to download membership form
Registration: vicepresident@vcfsfa.org.au or post to 30 Bradley Dr Carlingford NSW 2118

Speakers

- **Dr Linda Campbell** – Centre for Brain and Mental Health Research University of Newcastle (currently conducting a number of studies on VCFS)
- **Multilit** (Specialist Reading program)
- **Dr Carmen Jarrett** | Project Coordinator - Research & Education, NSW CAAH. Clinical psychologist, Dr Carmen Jarrett has extensive professional experience in the areas of developmental disability, child and family therapy and health promotion.
- **Choice Solutions** a highly respected and experienced provider of employment, training and assessment services for people with disabilities and **Esse** which has identified the need to provide educational workshops to help build self esteem and to assist individuals to make better choices in their lives.
- **Round Tables discussions** facilitated by professionals
 - Neil Nicoll – Anxiety and depression in adolescence & adults with VCFS
 - David Fitzsimons – Speech and Language (Cleft Palates, VPI etc...)
 - Multilit
 - Choice Solutions – Transition to work
- **Sam Bailey** – Special Guest www.sambailey.com.au (nothing to do with VCFS however very inspirational)
- **Neil McWhannell** – Heart Kids Australia
- **Maria Kamper** – President VCFS & 22q11 Foundation

Email registration to vicepresident@vcfsfa.org.au or post to 30 Bradley Drive Carlingford NSW 2118

Name: _____

Address: _____

Email: _____

Phone: _____

No. of Members and Guest (needed for catering): _____

Names of attendees: _____



VCFS & 22q11 Foundation

MEMBERSHIP FORM

All members receive a quarterly magazine, contact list, can attend meetings, attend the annual conference, receive minutes and if over 18 years old have the right to vote on foundation matters and elect board members.

Please tick

NEW APPLICATION		RENEWAL	
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DETAILS (Please write clearly)

NAME			
ADDRESS			
SUBURB		STATE	POSTCODE
PHONE	(H)	(M)	
EMAIL			
My interest in VCFS is Personal / Professional		Please specify	

AFFECTED INDIVIDUALS OPTIONAL INFORMATION

NAME	GENDER	DOB

Privacy of information

Information included in this form will be made available, as appropriate, to the board of the VCFS & 22q11 Foundation for the purposes of running foundation activities and producing the newsletter. This can include publishing a birthday list, naming individuals in reports of social events or labelling photographs taken at functions. The newsletter is distributed to our membership and contact list.

Please indicate below whether or not you agree to your family's details being used in these ways.

DELETE AS APPLICABLE: (THIS SECTION MUST BE COMPLETED TO ACTIVATE MEMBERSHIP)

- I **do / do not** give permission for the information provided above to be used by the foundation board in the quarterly magazine.
- I **do / do not** give permission to receive fundraising materials such as raffle tickets, invitations to dinners for the purpose of fundraising.
- Please **do / do not** include my details on the contact list. (The contact list is given to all financial members. Many parents have benefited from using this list to share information and experiences and arrange social activities.)
- I **do / do not** give permission for the foundation to contact me on behalf of professionals researching VCFS.

Signature _____ Date _____

ANNUAL MEMBERSHIP FEE IS \$20

Please **enclose \$20** in the form of a cheque or money order made payable to VCFS & 22q11 Foundation or fill in credit card details below which will cover membership until **30 June 2011**.

**POST THIS COMPLETED FORM WITH PAYMENT TO:
MEMBERSHIP 47 Third Ave Willoughby NSW 2121**

PLEASE BILL MY CREDIT CARD THE AMOUNT OF..... \$20.00 (for membership)

I WOULD ALSO LIKE TO DONATE..... (donations over \$2 are tax deductible)

TOTAL.....

Credit Card Authorisation

Mastercard or Visa (Please circle) Card Number _____

Cardholders Name _____

Signature _____ Expiry ____/____

VCFS & 22q11Foundation

BOARD NOMINATION FORM

22nd August 2010

Lorimar Dodds Auditorium,
The Children's Hospital Westmead

To: The Chair,
c/-

47 Third Ave Willoughby NSW 2068

I.....

of(address)

would like to stand for the following board position/s: (please tick)

- **President**
- **Secretary**
- **Treasurer**
- **Membership**
- **Public Officer**
- **Magazine Editor**
- **Learning Difficulties Coalition Representative**
- **General Board Member**

non board position/s: (please tick)

- **Local Area Representative**

I would also like to nominate for the position of

..... should he / she be willing to stand for the position.

Date

Signature.....

PROXY FORM

(to be completed if you are unable to attend in person)

To: The Chair,
c/-

47 Third Ave Willoughby NSW 2068

I.....

of(address)

appoint

as my proxy vote on my behalf at the Annual Board Election to be held on 22nd August 2010.

DateSignature.....