



PRESIDENT REPORT 2011

2010 - 2011

2010-2011 was a very active year for the VCFS 22q11 Foundation

VCFS 22q Christmas Party -December 12 2010

- Many families came along to the Willoughby Park for a family picnic day. Santa came and presented the children with some fabulous gifts.

World Rare Disease Day 28th Feb 2011

- I attended the Steve Waugh Foundation (SWF) World Rare Disease day at the Sydney Opera House on behalf of the foundation. There were guest speakers and Steve Waugh. They spoke of the need to raise awareness of Rare Disease. I currently working with SWF on their Rare Disease Day committee to assist in planning the 2012 campaign.
- In the evening the VCFS 22q11 Foundation hosted an event at Vivo Cafe with 60 guests for World Rare Disease Day. Tim Maddren of Hi 5 came along as our MC. Laurie Taylor from AGSA spoke as did Yvonne Zyrninski from the Australia Paediatric Specialist Unit. Sponsors of the night were Red Balloon and Magnolia Solutions



Steve Waugh Foundation WRDD event Sydney Opera House



Representatives from the many different Rare Disease groups with Tim Maddren from Hi 5 & Carly Nade

2010- 2011

Committee and Local Area Representatives workshop- March 12th 2011

- The VCFS 22q11 Foundation Board and Local Area representatives came together for a 1 day workshop and dinner at the Vibe Hotel in Surry Hills, Sydney. The day was a planning day for the future direction of the foundation. It was a great day and the group of 20 came up with a draft plan for the next 5 years.

The VCFS Board
& Local Reps



| Priority | Item | Progress | Date |
|----------|---|--|-----------|
| 1 | Teachers guide | The guide is complete and ready for review and editing | July 2011 |
| 2 | Parent guide - update and review | | |
| 3 | Camp | Funding has begun via the Everyday Hero, Treadmill walk, City to Surf, Marathon | |
| 4 | Contact list to be on members section of website | | |
| 5 | Consultant to lobby government | | |
| 6 | Family planning info sheet | | |
| 7 | Local rep stickers for brochures | | |
| 8 | Funding for IVF | | |
| 9 | Advice on awareness week activities | | |
| 10 | Guidelines for reps | | |
| 11 | Telling siblings | | |
| 12 | Magazine for other states info | | |
| 13 | Fundraising ideas on website | This has been included in the July Magazine | |
| 14 | Members section on website | | |
| 15 | Telling your child info sheets | Discussion to be held at the conference- topic was covered at the VCFSEF conference in july | |
| 16 | Review the (No) contact list | | |
| 17 | Local rep packs | | |
| 18 | Awareness packs to reps | | |
| 19 | Website to advertise all events | All that is required is to email to President to include on what's on page | |
| 20 | Medical checklist after diagnosis | A care plan has been formulate by the Children's Hospital of Wisconsin and will be uploaded to website shortly and available at conference | July 2011 |
| 21 | Medical board | In discussion with Dr Campbell, Dave Fitzsimons, Dr Huessler, Dr Wilson | |
| 22 | Update contact page on website for different age groups | | |

22q at the Zoo – 22nd May 2011

- Raising awareness in this worldwide campaign. We had 150 people attend the Featherdale Wildlife Park wearing our specially designed t-shirts and caps. It was a great family day. Due to the time difference we were the first country in the world to launch the 22q at the Zoo day. The day was an initiative by the International 22q Foundation, Dempster Foundation and CHOP. More than 13 countries, 65 zoo's over 3 continents participated. More than 10,000 people across the globe. I spoke with Macca on "Sundays with Macca" on ABC Radio on the day. There were also 2 newspaper articles about the day. As well as many social media posts & videos.



Stub out a dangerous habit

BYRAN Hoohan says the best time to quit smoking is straight away.

The program manager at the NSW Central West Division of General Practice says World No Tobacco Day today is an excellent opportunity for those who want to kick the habit.

He encourages smokers to talk to their family doctor about how therapies available on the Pharmaceutical Benefits Scheme

rather than provide profits for the tobacco industry," he said. "Tobacco smoking is one of the leading causes of preventable death and disease, as highlighted in the Federal Government's National Tobacco Campaign in Australia.

"Smoking causes 84 per cent of new lung cancers in men and 77pc in women. It kills approximately 15,000 Australians annually and costs the economy \$31.5 billion each year. I urge smokers to make an appointment with their GP and visit a pharmacy today to discuss how nicotine replacement therapy can be an investment in their health."

Nicotine patches have been listed on the Pharmaceutical Benefits Scheme as an aid to smoking cessation. The provision of the nicotine patches on the PBS requires a prescription.

Twenty-two reasons to raise awareness

By CANDICE FALCONER

CHARLI Kamper and her mother Maria were joined by 150 people last month to help raise awareness of a syndrome that affects one in 2000 people, yet remains relatively unknown.

Charli and Maria went to Featherdale Wildlife Park in Blacktown, in Sydney's western suburbs, on May 22 to raise awareness of 22q Deletion Syndrome, also known as VCF5, which Charli suffers from.

The All Saints' College student was diagnosed with 22q when she was four years old after her mother took her to four paediatricians.

"It is a common syndrome, but not many people know about it. It is the most common syndrome after Down Syndrome," Maria said.

The syndrome starts to delete chromosome 22 and up to 180 symptoms can result.

"It can depend on where the deletion starts as to what the symptoms are. Some include heart defects, cleft palates, autism, learning disabilities, immune disorders and mental illness," Maria said.

Charli, now 12, has the support of her family and her school, but as she gets older her symptoms may change. She currently travels to Sydney once a month for blood infusions.

"When she reaches adulthood there is a 30 per cent chance she will develop a mental illness such as bipolar or schizophrenia," Maria said.

After discovering her daughter had the syndrome, Maria started to research and find out what was available for Charli. She found the Australian Deletion Syndrome Foundation, and has been its president for three years.

"It has been going for 20 years and was the first foundation set up in Australia. The idea to raise awareness started in Philadelphia, America. People planned to go to the zoo and promote the syndrome," Maria said.

"I started in Philadelphia but quickly spread to 10 countries across three continents. Being on this side of the continent, we were the lucky country to launch the day at Featherdale Wildlife Park.

"It was a great day. The park was transformed into a 22q. Everywhere you looked, families and friends were enjoying a fabulous day of fun with the wildlife while spreading our message."

Maria is hopeful that the 22q syndrome may become a household name. For people wanting to know more, visit www.vcf5.org.au.



RAISING AWARENESS: Maria Kamper and her daughter Charli were part of the first 22q awareness event at the Featherdale Wildlife Park.

Mother paid for hitman, court hears

A WOMAN arranged for her mother and sister to help organise the contract killing of her estranged grazier husband, a Sydney jury has been told.

Prosecutor Terry Thorpe said Helen Ryan spoke to her sister about organising a hitman and obtained \$10,000 from her mother as a post-payment for the contract.

He was opening the crown case yesterday in the NSW Supreme Court at the trial of Ryan and her mother, Connie Coulter.

They have pleaded not guilty to murdering Jeffrey Ryan, 48, on October 23, 2009 at Durl, near Tamworth.

The crown alleges both women were part of a joint criminal enterprise, the object of which was to have Mr Ryan murdered.

Mr Thorpe said the crown case was that they both knew for a period of time before Mr Ryan was shot dead that he would be murdered.

He said Ryan spoke to her sister, Connie "Cooz" Coulter, whom she believed had certain contacts to arrange the murder.

He told the jury Connie Coulter pleaded guilty to conspiring to murder and had been sentenced for her participation in the events.

She is expected to give evidence at the trial and Mr Thorpe said he anticipated she would tell the jury Ryan told her she wanted her husband killed.

Ryan allegedly told her sister: "I can't take any more of the physical abuse. I want to get rid of him so the whole lot is mine."

Mr Thorpe said the crown alleged Connie Coulter provided \$10,000 to Ryan, knowing that money was the "post payment on the contract that she had taken out on the life" of Jeffrey Ryan.

Junior sport TEAM OF THE WEEK

Does your team deserve to be our Team of the Week? If so, tell us why!

Email a photo and details about your team to mail.westernadvocate@ruralpress.com

WESTERN Times 11,200 copies home delivered each week!

NEWS

Raising awareness

22q Deletion Syndrome (also known as VCF5) is a rare genetic condition that affects one in 2000 people. It is a common syndrome, but not many people know about it. It is the most common syndrome after Down Syndrome.

Nature trail cut

NSW Environment Minister Ian Dray has announced a \$10 million grant to fund a nature trail in the Blue Mountains National Park. The trail will be a 10-kilometre loop through the park's natural beauty and will be a great place for families to enjoy the outdoors.

Did you know the Child Care Rebate now has more payment options?

The Child Care Rebate now has more payment options. You can now choose to have your rebate paid to your child care service, or to your bank account. This means you can get your rebate faster and more easily.

Child Care Rebate helping families with the cost of child care.

June Long Weekend Trading Times

| HAYMARKET | | FLEMINGTON | |
|------------------------|-----------|-----------------------------|--------------|
| Wednesday 8 June | 9am - 5pm | Friday 10 June | 9am - 4.30pm |
| Thursday 9 June | 9am - 5pm | Saturday Fresh Food 11 June | 9am - 2pm |
| Friday 10 June | 9am - 5pm | Sunday 12 June | 9am - 4.30pm |
| Saturday 11 June | 9am - 5pm | | |
| Sunday 12 June | 9am - 5pm | | |
| Public Holiday 13 June | 9am - 5pm | | |

For service times, parking & locations: www.godfysmarkets.com.au

Blacktown Advocate- Western Sydney

Western Advocate- Central West NSW

Courses: July 2011

- I went to 2 courses for the foundation. Sustainable Fundraising and Secrets of Successful Boards. I have applied for a grant to complete the Governance course. We have also been approved for DonorTec program (a program that offers reduced price software)

VCFSEF 18th International Scientific Conference July 15th - 17th

- Louise Hall, Andrew Dunkerly and I attended the conference in New Brunswick NJ USA. The conference was over 3 days with more than 80 presenters, moderators and professionals. I presented at the conference on The Importance of Support Groups and using Social Media. I will present a brief of the conference later today.

City to Surf 2011

- Belinda Cropper Roberts and Charlie Champions entered the City to Surf to raise money and awareness of VCFS. With the assistance of a very good friend of the family they hope to continue to raise awareness and money to help our families go on a holiday camp. They had their own shirts made and have done a fabulous job.
- Rachel Mangan also entered the City to Surf and has raised money to assist our foundation.



VCFS 22q11 Foundation Awareness week 2011 - 22nd August - 28th August

- Many of our members have been hosting morning teas, Pink and Blue days Etc.. During awareness week. There has been a number of Newspaper articles about the syndrome. Well done to everyone.
- The VCFS 22q11 TV commercial has been playing all year on Ch9 and will also be aired again during August nationally on 9, Win and NBN as well as pay TV, thanks to Lucy Jackson , Tex Whitney (producer) and Scott Corcoran of WinNBN TV



Tamar Stanford our Illawarra
Rep in the local paper

24 hour Treadmill for Awareness 25th & 26th August

- Caroline Dwyer VCFS 22q11 Foundation member took it upon herself to raise awareness by doing a gruelling 24 hour treadmill walk. Caroline has raised funds and awareness. Caroline was sponsored by many organisations who offered donations of money, prizes to raffle etc.. Other members of our foundation went along to support as did a huge contingent of her friends. Well Done you superhero!!!!!!

NEWS penrithpress.com.au

BRIEFLY

Police target drink

PENRITH: Operation Pant will run this weekend from Friday to Saturday night. Police will be targeting alcohol-related behaviour in and around the Penrith area, particularly traffic offences and behaviour at licensed premises. Crime manager detective Inspector Grant Healey said the idea behind the operation was to encourage people to drink responsibly. "We want to remind people at the start of the night to drink to have fun, not drink to get wasted," he said.

Change of menu

PENRITH: Residents who enjoy getting a feed from the mobile food van at Tench Reserve will see new faces come September. Colin and Kerl Maples were awarded the tender to provide a kiosk at the reserve, near the public boat ramp area and the boat trailer carpark. Their lease begins on September 1.

Top voters

A REVIEW of voting behaviour at last year's federal election has shown that local voters are among the most conscientious, with Macquarie showing the fifth highest turnout in the state at 97.5 per cent and Lindsay not far behind with 95.9 per cent. Both electorates also showed relatively low percentages of informal votes, with Macquarie at 5.48 per cent and Lindsay at 8.17 per cent.

Caroline puts best foot forward for sick friend



SOUTH PENRITH

ALEXIS CAREY

CAROLINE Dwyer is a true everyday hero.

After a close friend was diagnosed with the little-known condition velo-cardio-facial syndrome (VCFS), she decided to show her support by launching an awareness campaign.

Drawing on her two feet and boundless energy, the South Penrith mother of three will help combat VCFS with an 24-hour walkathon next week to raise money and awareness of the condition.

VCFS, also known as 22q11, is a genetic syndrome caused by a deletion on the long arm of Chromosome 22.

The condition affects people in countless ways, from cleft palates, congenital heart defects and psychiatric problems.

Mrs Dwyer said she wanted to do her bit to raise awareness and increase early detection.

"VCFS is one of the biggest syndromes but because there is so much variety in symptoms it can be hard to detect," she said.

FAST FACTS

- **WHAT:** VCFS 24-hour walkathon
- **WHERE:** Penrith City YMCA, Pattys Place
- **WHEN:** From 4pm on Thursday to 4pm Friday
- **HOW YOU CAN HELP:** Raffle tickets are available at the gym's reception. Donations can also be made to support Caroline at everydayhero.com.au or vcfsa.org.au

"People still die from this, so I decided to do a 24-hour treadmill walk because I thought it would make people take notice."

Mrs Dwyer will have just five minutes' break every hour, and she urged the community to come along and walk with her.

"We have raffle tickets and so many huge prizes to give away, people have been so generous and I would love people to come down and walk with me for a while and learn more about VCFS," she said.

Mrs Dwyer has been training for an average of 25 hours a week to prepare for the big day.

Caroline Dwyer is participating in a 24-hour walkathon to raise money and awareness of VCFS. PHOTO: MATT O'LELL/NAN

Caroline was featured in The Penrith press newspaper

VCFS Iron Man – Scott Longden

- Scott has been competing in many Iron Man events and Triathlons to help raise awareness and funds for VCFS. We thank him for his dedication and we back him all the way. Keep on running Scott.

Association for Genetic Services Australasia (AGSA)

- I have been regularly attending the AGSA support group leaders meetings. These meetings were established so that the support groups could work together sharing ideas and support mechanisms

Learning Difficulties Coalition (LDC)

- Louise and I have attended the LDC meetings this year. The LDC has written on behalf of all the foundations they represent including VCFS 22q11 for many government enquiries and requests for information to assist with services for those with learning difficulties.

Social Media

- We have been using social media regularly to raise awareness and support each other on this journey.

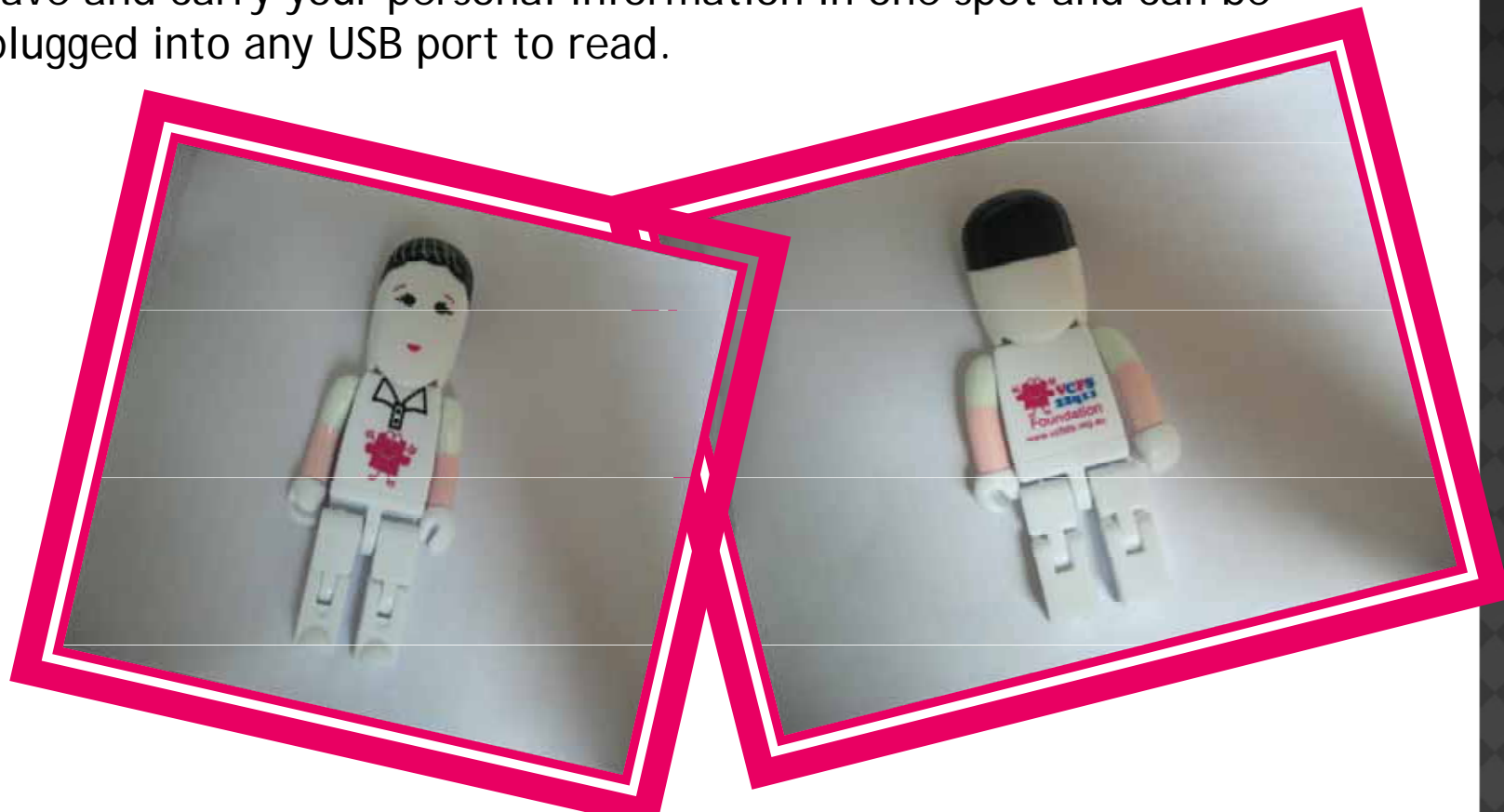
Our FB site has 592 members. We have formed friendships with the Dempster Foundation, International 22q11 Foundation & VCFSEF and many other groups to raise awareness using Facebook and twitter.

Over the past 2 weeks the Dempster Foundation has had a bus visiting many cities in the USA with the slogan “Strike out 22q” Ryan Dempster is a famous baseball player for the Chicago Cubs” and he has a child with the deletion. Fantastic work!



New Information and Guides

- USB sticks - We have purchased VCFS 22q11 Foundation USB sticks. The sticks are a valuable resource and have been preloaded with guides, booklets, brochures, Plan of Care etc on them. There is also plenty of space left on the sticks to put your own medical records or reports. Each family here today has received one. They will be available to people who have not attended today for a small fee. A great way to save and carry your personal information in one spot and can be plugged into any USB port to read.



- Wrist Bands- We had 500 wrist bands made and they have almost all been sold by many of our members during awareness campaigns.



All in all it has been a very successful year for the foundation . All of the board and representatives are volunteers. I want to thank you all for your great work & dedication. I encourage all of you here to volunteer from time to time. It is a very rewarding experience.

I believe we will continue to grow as the years move on.

I am proud to be your President and I hope to continue over the next few years.

Maria Kamper

