From the Editor’s Desk

Green is synonymous with so many things: nature, ecology, organic lifestyle, lushness, freshness, newness, peace, springtime, and most certainly the land of Ireland. I hope this spring issue of the VCFSEF newsletter will conjure up many of those images and entice you to join us for the 20th Annual International Scientific meeting of the Velocardio-facial Syndrome Educational Foundation in Dublin, Ireland from July 18-21. Read on to learn some of the educational and social highlights of the conference and all that the city and hotel venue has to offer.

Please visit our website at www.vcfsef.org for specifics on how to participate in these programs as well as register for the conference and social events.

The VCFSEF annual meeting is a fabulous time to reconnect with old friends and make many new ones. I am looking forward to raising a glass of good cheer with many of you this year. To that end, I make this toast to all of us as we embark on our travels.

May the luck of the Irish
Lead to happiest heights
And the highway you travel
Be lined with green lights.
~ Irish Toast

Register for the 20th International Scientific Meeting of the Velo-Cardio-Facial Syndrome Educational Foundation, Inc
http://www.22q11ireland.org/events/vcfsef-2013---WELCOME
GREETINGS FROM THE PRESIDENT

Anne Lawlor  
VCFSEF President

Hello everyone and greetings on this St. Patrick’s Day from a cold place in Dublin, Ireland! The abstracts are in for the conference which makes everything feel “so real.” It’s actually happening! What once seemed so far away is almost upon us.

We are excited and looking forward immensely to July (we hope the weather will be warmer too!). Here’s a little information about our conference venue The Regency Hotel Dublin.

Hotel amenities include an onsite restaurant and lounge, a fitness center, and an indoor swimming pool. Being three miles from the Dublin International Airport and Connolly Train Station makes it easy for guests to reach the Regency Hotel Dublin. Onsite parking and free airport shuttle service are also available. The hotel itself has a rich history dating back to the 18th century. Built in 1900, the Regency Hotel Dublin was originally a stately home. Many of the 18th century features are seen throughout to include original tiles, high ceilings, mahogany staircase, period style furniture, and a large elegant hallway.

For those of you who like castles, here is Malahide Castle, not too far away and always worth a visit.

The longest tree-lined residential avenue in Europe is around the corner. For those who like to stroll (or run), the avenue is the ideal place to do so. Taking a left turn onto to Griffith Avenue and walking to its end will almost land you at the casino Mariano where you can visit a little gem.

Dublin City itself has a host of attractions. Some things to do are the Hop on Hop Off Dublin City Tour, buy your tickets in advance then hop on the early morning shuttle to the City and see what all the fuss is about! Visit the Guinness Visitor Centre. Learn all there is to know about Guinness, including how to pour your own pint. Finally see how the experts do it and enjoy a pint of "The Black Stuff" while enjoying the panoramic views of the City from The Gravity Bar.

National Museum of Ireland and The National Gallery - No trip to Dublin is complete without a visit to one of our two main cultural institutions, the beautiful buildings that house them are worth the visit alone & best of all they are totally free of charge.

Kilmainham Gaol - Of key importance in the history of Irish rebellion - well worth a visit as is Dublin Castle which houses the Chester Beatty Library, a treasure-house of, well, treasures! Free guided tours in the Library are available at 1pm each Wednesday, 3pm & 4pm on Sundays.

Of course there is lots more to do and see and whatever it is our visitors in July choose to do we hope that you will enjoy your visit to what is still one of the friendliest cities in the world.

Best and warm wishes from Anne and the Irish 22q Group.
CONFERENCE HIGHLIGHTS

We have over 50 abstracts submitted from across Europe, The Middle East, the US, and Australia addressing genetic, neurological, psychiatric, cognitive, communication, education, and other psycho-social issues. Scientific presentations will include Dr. Stephan Eliaz, Dr. Doron Gothelf, and Dr. Ann Bassett addressing "Psychiatric Issues across the Ages". We will also have Dr. Tony Simon speak on "Integrating Cognitive and Affective Factors to Understand Mental Health in Youth with Chromosome 22q11.2 deletion syndrome/VCFS." Dr. Bronwyn Glaser will speak about social cognition and Dr. Robert Shprintzen will provide us with updates on surgical interventions, speech outcomes and more.

We will again offer "Meetings with the Experts" in the morning and midday. These will include informal round table discussions with experts in communication deficits, resonance/articulation disorders, psychiatric issues for children, adolescents, and adults, and of course educational concerns with specific focus on post high school years. Ireland’s Government Minister for Disability, Equality and Mental Health will be joining us for the Welcome Reception on the Thursday evening when we will, of course, provide some wonderful Irish entertainment.

Special “Kidzone” activities are being planned for the “wee ones”, kids, and teens. A social media workshop is among the presentations specifically for the older teen/young adult.

Over the years, the VCFSEF has showcased many wonderful talents of our attendees, young and old. Last year, Tessa Koller, an artist and fashion designer who has VCFS, put on a runway show of her latest designs giving our pre-teens, teens and adults a chance to “shine” under the spotlight as models. They all got to “step out” to the techno-musical skills of Mike Berg, another talented teen with VCFS. Tessa returns to Dublin with her latest fashions this year. But what is a fashion show without some “flash”? The 22q11 Ireland group is excited to announce that Rick Guidotti, a fashion photographer with a passion for discovering and sharing the special beauty of children with conditions that affect their physical appearance, will be presenting his Positive Exposure project at the conference Gala on Saturday night, July 20. Please check out Rick’s website to learn more about his incredible work at http://positiveexposure.org/.

A special theme promoting the 22q11.2 unique side of you will weave its way through all the social programs. In addition to the runway and photography show, the second annual Ability Exhibit will be on display which will feature original works of art, crafts, writings, or photos that depict an individual’s interest, passion, and/or talent that make each of them unique. More information about 22q11.2 Uniquely You follows in this newsletter.

22q11.2 UNIQUELY YOU

The VCFSEF and 22Q11 Ireland group warmly invite all attendees of the 20th International Scientific Meeting to a special gala event on Saturday night, July 20th at the Regency Hotel in Dublin, Ireland, home to the conference.

The gala will introduce the 22Q11.2-Uniquely You Program which will feature the exceptional interests and talents of individuals of all ages with VCFS/22Q11.2 DS. Bring an item to the VCFS International Meeting to in the 22q11.2 Uniquely You Exhibit. This can be an original work of art, craft, writing, or a photo collage. Let a picture express the things you like to do or show something new you have learned or simply enjoy. Collections or ribbons of achievement work too. Show off with your participation and help to build a Flash Talent / Ability Exhibit that celebrates what everyone is doing.

The Uniquely You Program will feature other art presentations during the evening. For a second year a Flash Fashion Event will be held featuring the original clothing designs from the studio of Tessa Koller. Tessa, is a fashion designer and working artist using her abilities and talents to create colorful, wearable fashion. She has VCFS and is passionate about supporting the talents of others and increasing awareness about the deletion syndrome worldwide.

We need volunteers from our conference attendees, their siblings, or parents to present Tessa’s designs at the gala. If the “unique you” would like to walk the runway and strike a pose, Tessa Koller needs several girls ages 10 to young adult, to model her designs that evening. And guys we need your help too. If your ability is taking photographs or music production, or you would like to walk the runway the show always needs extra skills to really make it “pop” for the audience.

Don’t be shy, shine instead, and join the 22q11.2 Uniquely You Flash Exhibit and Fashion Event.

For more information and to register for participation in the Flash Talent Exhibition, and Fashion Event, contact Margie Koller-Podjasek taolife7@gmail.com.

The future is not set, there is no fate but what we make for ourselves.
~Irish proverb
TRAVEL TIPS FOR IRELAND

TRAVEL INFORMATION
On arrival to Dublin Airport we want to ensure that you can easily make your way to your final destination in Ireland. Our conference office will recommend the best routes depending on your selected accommodation property if booked with the conference desk.

**Airport to Hotel - Dublin Bus**
www.dublinbus.ie
The number 16 bus is the best route to take. Bus price from the Airport to the Hotel is approximately €2.50 per adult and €1.30 per child. Ensure you have coins with you!
The Regency Hotel is ideally located on the main bus corridor between Dublin City Centre and the Airport. The journey time depending on traffic can take up to 40 minutes on peak times.

**Airport to Hotel – By Taxi**
A journey from Dublin Airport to the Hotel should average at €20.00. There is a large taxi rank just outside the arrivals hall at Dublin Airport.

**Airport to City Centre**
If you are travelling from Dublin Airport, direct into the city centre
Air Coach [http://www.aircoach.ie/](http://www.aircoach.ie/)

**Hotel to City Centre**
The journey time on the bus is between 10 and 15 minutes depending on traffic and the cost of a single journey from the Hotel to the city is just €1.95
A Taxi's from the Regency Hotel to the city centre should average €10.00

Optional Tourism Information
It may be your first time to Ireland but we want to ensure that you make the most of your visit and see what Dublin has to offer.
Other Places to Visit:
- Dublin Hop on Hop off Bus tickets (kids go free- 2 under 12 with 1 paying adult) Make reservations for this bus tour when you register for the conference.
- Leprachaun Museum- a must see for any small visitors hoping to catch glimpse! [www.leprechaunmuseum.ie](http://www.leprechaunmuseum.ie)
- Natural History Museum- Take Dublin Bus into the city centre and visit this free destination [www.museum.ie](http://www.museum.ie)
- National Wax Museum - see the stars and get your picture taken with your idol [www.waxmuseumplus.ie](http://www.waxmuseumplus.ie)
- Dublinia - This medieval location will bring you back in time. [www.dublinia.ie](http://www.dublinia.ie)
- Botanic Gardens- Free to visit and beautiful [www.botanicgardens.ie](http://www.botanicgardens.ie)
- Skyline at Croke Park - This experience is for those not afraid of heights! Walk on the edge at the top of Dublin’s Croke Park. (1.2m high to go on tour- for the adventurous) [www.crokepark.ie](http://www.crokepark.ie)
- Day Trip to Tayto Park Visit this small adventurous park, the home of Tayto Crisp! [www.taytopark.ie](http://www.taytopark.ie)
- Dublin Zoo - Visit this world famous park ideal for your families day out in the city centre. [www.dublinzoo.ie](http://www.dublinzoo.ie)
- Malahide Castle- Visit the gardens and castle- hopefully you won’t see any of the resident ghosts! [www.malahidecastle.com](http://www.malahidecastle.com)
- Guinness Storehouse – Visit the home of Guinness and travel to the 5th floor to see the wrap around view of Dublin City. [www.guinnessstorehouse.com](http://www.guinnessstorehouse.com)
- Book of Kells- step through the wooden doors into Trinity College and visit the home of the Book of Kells [http://www.tcd.ie/Library/bookofkells/plan-visit/](http://www.tcd.ie/Library/bookofkells/plan-visit/)

Check at the registration desk at the conference
MODELS WANTED

Calling all preteens to young adults who will be attending the 20th Annual International Scientific Meeting of the Velocardiofacial Syndrome Educational Foundation in Dublin, Ireland this summer. Tessa Koller, an up and coming fashion designer from Wisconsin who has VCFS/22q11.2DS, will be presenting her 2013 line at the conference gala, Saturday night, July 20. She is looking for volunteers ages 10 and older (sizes 2-14 US/32-44 European) to model her designs. Guy models and/or helpers are also needed. NO EXPERIENCE IS REQUIRED!

If interested in being a model or assisting with the event, please send an email by May 15, 2013 with the following information to taolife7@gmail.com. NO experience is needed!

Name of Model:
Email or phone number to contact:
Age:
Height:
Measurements: for bust, waist and hips

Please attach a full length photo to the email. All volunteer models are asked to bring black flats, black/white leggings or tights, belts and other accessories, make up/hair products (optional) to the show in Dublin.

Not interested in modeling, but still want to help? Let us know
Deadline to volunteer is May 15, 2013.
Questions? Email: taolife7@gmail.com

19TH INTERNATIONAL SCIENTIFIC MEETING OF THE
VELO-CARDIO-FACIAL SYNDROME EDUCATIONAL FOUNDATION
AUDIO TAPES FROM CONFERENCE

Not able to make the conference in 2012 in Toronto? You can order an audio copy of the lectures on a MP3 format.
More information can be found at www.vcfsef.org or http://www.softconference.com/vcfs/
SPOTLIGHT ON SUCCESS

Last issue we met Aine Lawlor, an adult with VCFS who set goals for herself to become a special education paraprofessional at the school she attended when she was younger. Through her diligence and hard work, Aine achieved this goal and has gone on to inspire others with disabilities to become all that they can and hope to be. In her own words she writes,

*Kids with 22q need to believe in themselves and they need to believe in their dreams, their goals. They need to believe that they can have a life like everyone else, get married, have kids and have a job. They need to believe in themselves. They need to believe that they can do well in school – they can go to college and get an education*

*Parents need to believe in their kids, need to respect their kids. They need to accept the fact that their child has 22q or their child won’t be able to live their life. When the parent accepts it the child will too. Most number one thing to do – accept what you have. You do that and your life will change.*

What follows are comments from a volunteer who helped Aine over the years, but now appreciates all that Aine did to help her.

Our Children as Teachers
By: Grainne Mooney, friend and volunteer

*I have known of 22q11.2 Deletion Syndrome for only 7 years but my experience has been an eye opening one! I used to get annoyed at the person who was taking too long at the checkout in a shop or the person who didn’t seem to know where they were going and slowed me up in the process or the person who rang me in work (I work in pensions) to ask me what they are paying for, after all I thought to myself “How can anyone not know what they are paying for?” Then in 2004 I began my journey with 22q and it soon became obvious to me that we are all living with disabilities to varying degrees. Sure I don’t have the deletion myself, I don’t have a child or a sibling with the deletion but as long as there are people with disabilities in the world can any of us say we are not living with disability? When one sees a person with Downs Syndrome for example, one knows immediately but when the effects of a syndrome are not visible therein lies a challenge for us all.

For me it has meant that when I come across someone taking longer than usual at the checkout then maybe there is a good reason. Maybe they have difficulty understanding money and as for the person who doesn’t seem to know where they are going, well maybe they have an invisible disability which means it takes them longer to sort out in their mind how they get from A to B! As for the person who rings me to ask what are they paying for? Perhaps they really do not know what they are paying for and they are not ringing up just to upset the smooth running of my day! I now know that people with 22q11/2Deletion syndrome work out things differently than me. Their brains are wired differently than mine. They reach their destination using a less conventional route, but they do get there and who am I to make their journey more difficult? It behooves us all to be aware of invisible disabilities and those with such disabilities have so much to teach us if we let them. I know my good friend Áine has taught me a lot and I will always be grateful to her for that!*

Meet another talented young man from the United Kingdom (Thomas Hawley) who has donated some of his original works of art for the VCFSEF on-line auction.

*My name is Tom and I am 13 years old. I was born on the 4th of December, 1998, and was diagnosed with VCFS when I was 2 years old. I have always loved pens and pencils, drawing and doodling from a young age, but when I was ten, I watched an art programme on television all about water colour paintings, and I loved it!
Spotlight on success

Continued from page 6

The programme was amazing so I recorded it and watched it over and over and over again. Then I asked Mum and Dad to buy me brushes and paints and special paper so that I could start painting.

I started to paint brilliant paintings that my family loved. Then we showed them to other people and they loved them too.

They wanted to buy them so we started to sell them, and before I knew what was happening, Mum was posting my paintings to people from all over the world…amazing!

Sometimes life gets me down and I can get very anxious, my painting takes me away from all that and it makes me feel calm and capable of doing anything. I also love music, I love rock music and play a mean electric guitar!

My Mum and Dad are great! They support me with whatever I want to do and they are always there for me through thick and thin.

Thank you for reading this, I hope you can take time to look at my website www.tommyart.co.uk

VCFS/22q11.2 DS COMMUNITY EVENTS

May 2013
5/19/13 22q at the Zoo
http://www.22q.org/

5/24 - 5/25/13 The Word of 22
Rome, Italy
segreteria@aldel22.it

July, 2013
7/18 - 7/21/13 20th International Scientific Meeting of the VCFSEF
Dublin, Ireland
www.vcfsef.org

August, 2013
8/31 - 9/1 Texas VCFS/22q
Annual family retreat
www.vcfstexas.com

Coming in 2014
7/17 - 7/20/13 21st International Scientific Meeting of the VCFSEF
Las Vegas, NV
Happy Spring to all! In spite of the snow (Midwestern US, and Dublin Ireland), rain, and cooler temperatures, spring is here. For those of you with children in school, this means the days are longer, and there are new challenges to get them in to bed at a reasonable time. It also means that the end of the school year is rapidly approaching, and summer is around the corner.

The winter months have been busy for VCFSEF. On February, 28, 2013, I attended and spoke at a rally at the Texas State Capitol for the National Organization of Rare Diseases day. Although VCFS/22q11.2 deletion syndrome is not “rare” in terms of its prevalence, I think each family impacted by this diagnosis will agree that the knowledge among professionals about this syndrome is “rare”. And for this reason, it was important to participate in NORD’s national and international day.

March 2nd and 3rd saw the 3rd annual Walk for Awareness. Thank you to Bridget Goad in Tennessee, Rebecca Osberg in Sulligent Alabama, Michelle Hannah in California and Angela Helvey in North Carolina for continuing to “carry the torch” for this event. Every time an event like this is held, we reach out to at least one person who did not have knowledge about VCFS/22q11.2 deletion syndrome. This is a grassroots way to increase the awareness of this syndrome, and an effort everyone can participate in.

On April 6, 2013, the VCFSEF sponsored another Tessa Koller Knowledge is Hope seminar, working with 22q11 North Carolina, Kelly Schoch and Vandana Shashi. evening, the young adults and their parents were treated to supper and bowling through a generous sponsorship by the Dempster Family Foundation. This educational seminar was also held as a webinar -- the second webinar for VCFSEF.

As spring becomes summer, VCFSEF is hard at work putting together the 20th International Scientific Meeting of the Velo-Cardio-Facial Syndrome Educational Foundation, Inc. in Dublin Ireland, July 18 – July 21, 2013. Over 50 researchers submitted abstracts for this meeting, and the faculty will include researchers from the US, Europe and Australia. More information about the meeting can be found on our website at www.vcfsef.org.

In closing, I would like to encourage each of you to become involved in some type of grassroots “awareness” campaign. Perhaps, you are the parent of a child in elementary school, and could consider a “read-a-thon” that would raise awareness of VCFS/22q11.2 deletion syndrome among families at your child’s school. Or, at your company, you are able to suggest a fundraising event like “Pumpathon” hosted by Matt Slayton at the Circuit Bouldering Gym” or a “Bike-a-thon” at a local gym. Through these activities, you can make an impact in your community by raising awareness, and helping with fundraising for the VCFSEF, a non-profit, all volunteer organization that can only continue to put on these valuable programs and activities with your donations.

Dianne Altuna

*Alone we can do so little; together we can do so much.*

~Helen Keller~
**3RD ANNUAL WALK FOR AWARENESS**

Angela and David Helvey organized the walk in Sanford North Carolina. Here’s Angela’s description of the walk, and what this type of campaign to raise awareness means to her.

This year for the 3rd Annual VCFS Awareness Walk, along with wearing our t-shirts, I made little paper flags to hold with the VCFS logo and website. Another thing I did this year was make up a poster board with the fact sheet for VCFS or 22q11.2 Deletion syndrome, attaching little pieces of paper to rip off for people to look up the website for VCFS. This was displayed at my son’s speech therapist office for parents to read in the waiting room. So far two parents that I know of have asked about more information, or asked questions. Awareness is now very important to me because I am 27 weeks along. I have had a couple of doctors so far during my pregnancy not understand that I will not have another baby with VCFS. I had had to pass out information and teach them that I do not carry the gene nor does my husband. I have also been handing out information to nursing students or other pediatric facilities that I come across during my care being pregnant. I am happy to get the word out about VCFS or 22q. I believe that if every parent, doctor, friend, nurse or family can help spread the awareness for VCFS of 22q, then people will say more often, “Ya, I know about that syndrome and I am aware”.

VCFS Awareness Walk "TEAM BRILEY"
Bridget Goad and her friends and family gathered in Kingston, Tennessee March 2nd. In spite of the cold temparture, her group celebrated raising awareness of VCFS/22q11.2 deletion syndrome.

Rebecca Osberg is very active in her community raising awareness of VCFS/22q11.2 deletion syndrome. Rebecca organized a walk in her community, but did not stop there. She also contacted Senator Reed, who signed a resoulution recognizing Rebecca’s “valuable efforts to raise awareness of velocardiofacial syndrome”

Rebecca, was recently interviewed by Allie Ware of WTVA in Tupelo, Mississippi.
On April 6, 2013, I had the privilege of being a part of the Knowledge is Hope seminar held at Duke University. This seminar was the 2nd seminar held by the VCFSEF, and co-sponsored by 22q11 North Carolina for young adults with VCFS/22q11.2 deletion syndrome and their parents. In addition to the “live seminar, a webinar for other parents across the country and world was offered.

In all over 100 families received information from Dr. Matcheri Keshavan, psychiatrist, Glenna Osborne who presented on employment options, Hal Wright, financial planner and Adrienne Villagomez and Keith Errickson on post-secondary education opportunities. Mary Mayo, parent and Dr. Vandana Shashi presented a panel on how to support relationships. Dr. Steve Hooper, educational psychologist facilitated a discussion with the young adults on what they would like their parents to know and shared their insights with the parents in a lively and informative session later in the day.

Families traveled to North Carolina from Georgia, Virginia, South Carolina, New York, New Hampshire, Connecticut and Florida to hear from this panel of researchers and professionals. Those who attended the webinar were from across the US and Australia.

Those families who remained in Durham for the rest of the day were treated to a fun evening of bowling and dinner thanks to the generous grant from the Dempster Family Foundation.

Mary Mayo, of the 22q11 North Carolina support group organized an online silent auction to help support this event. Articles for sale included a pair of tickets to the North Carolina Hurricanes Hockey game, a blouse created by Tessa Koller, and an original painting by Thomas Hawley. Thank you to Pete Hautem for donating the printing of a banner and to others who donated items for the auction.

This one day seminar could not have happened without the coordination of Kelly Schoch (Genetic Counselor at Duke University) and Dr. Vandana Shashi (Geneticist at Duke University). Thank you Kelly and Vandana for all of your help.

The Tessa Koller Knowledge is Hope Fund was created with a generous donation by Paul and Margie Podjasek in honor of their daughter, Tessa Koller. This fund will support the on-going educational meetings for young adults and their parents.

For more information about the Tessa Koller Knowledge is Hope Fund, or to donate to this fund please go to www.vcfsef.org.

JD Mayo, Tyler McIntyre and Connor Devlin enjoying an evening of bowling in Durham, North Carolina.
VCFSEF REGIONAL UPDATES

Latin and South America
Dr. Tony Ysunza

Saludos desde Latinoamérica a todos los miembros de la VCFSEF.

A series of scientific conferences were held in the beautiful city of Santiago de Chile, Chile, in South America March 4-11 of this year. The 22q11 Chilean Foundation, headed by Mrs. Patricia Jessam, President, Dr. Gabriela Repetto, Medical Geneticist and Fga. Mirta Palomares, Speech-Language Pathologist, worked very hard to put on an interesting program. The conferences were supported by the Medical School of the Clinica Alemana (German Clinic) of the Universidad del Desarrollo, the Gantz Foundation (a non-for-profit organization dedicated to the care of patients with cleft palate), the Hospital Calvo Mackenna (Children’s Hospital) and the Council for Science and Technology from Chile. Dr. Marcela Llorente, Pediatric Immunologist, Dr. Rosemarie Fristch, Psychiatrist, Dr. Ivanhy Ureta, Psychiatry resident, and yours truly were invited to participate in this event.

The program included a review of several patients with VCFS at the Hospital of the Gantz Foundation, a workshop with the research group of the Medical Genetics Laboratory of the Medical School of the Clinica Alemana, a scientific conference at the Clinica Alemana and a conference for parents and professionals. It was an extremely busy week!

In the conferences, Dr. Llorente provided parents and professionals with an excellent review of vaccines for children: which vaccines should always be applied and which vaccines should be delayed after an adequate immunologic evaluation. Doctors Fristch and Ureta addressed psychiatric issues in patients with VCFS. Dr. Repetto explained the complicated genetic issues in terms which could be understood by all the parents and also presented new important research projects which are being carried out at the Medical School of the Clinica Alemana. There was also a great deal of discussion among the surgeons about pre-operative imaging studies before velopharyngeal surgery, surgical techniques and the important role of speech pathology treatment in patients with VCFS.

The best presentation was given by Inaky, a 15-year-old gentleman with VCFS. He is the son of Patricia Jessam, President of the Chilean Foundation. He shared his personal experiences and challenges. His presentation was excellent and touching as he encouraged all patients and families to “seguir adelante” (go ahead) and not be discouraged. I must say I felt privileged and humbled to share the panel with Inaky, who by the way, is a diehard fan of the Colo - Colo (a very popular Chilean soccer team). There were a lot of questions by the parents who attended the conferences. A group of volunteers from the Medical School provided child care during the sessions which included organized soccer matches and other activities.

In summary, quality of care and support that the group of families and professionals in Chile are providing for patients with VCFS is of the highest quality. I felt very fortunate to able to play a small part in this great event.

Editor’s Note: Dr. Ysunza has relocated to Beaumont Health System in Michigan, but remains our dedicated Latin American regional director for VCFSEF.

Australia
Maria Kamper, President VCFS 22q11 Foundation in Australia

The VCFS 22q11 Foundation has been working quietly of late. We have been working to secure our condition on an initiative in Australia that would see our kids receive funds for early intervention. It’s a tough job but we feel that we may get somewhere very soon.
Regional Updates
continued from page 11

Plans are underway for our 2013 Family Camp. The 2012 camp was a huge success and we are looking at holding this year’s camp in August. All people affected by the 22Q11.2 Deletion in Australia are welcome.

We have also produced our own “Living with 22q” booklet. Based on the USA booklet we have re-worked it for Australia. We are also in the process of updating our current brochures and flyers. Efforts are underway to establish a coordination centre and are we are hoping to have one before the end of the year. We are extremely excited that a clinic in Melbourne will begin this month. We have been avid supporters of the establishment of this clinic and are proud to have had a say in it.

The VCFS 22q11 Foundation is also excited to once again, be a part of the world wide “22q at the Zoo” on May 19th this year.

Finally our president is looking forward to coming to the VCFSEF conference in Dublin in July and catching up with all of you.

**KNOWLEDGE IS HOPE BROCHURE**

The "Knowledge is Hope ©" brochure published by the VCFS Educational Foundation, Inc is an 18 page booklet that contains basic information about velo-cardio-facial syndrome for providers, families and others interested in learning more about VCFS. It provides an essential overview about the syndrome to facilitate proper diagnosis and treatment. Order copies for you patients or care providers. You can order brochures directly from the foundation's web site at: [http://www.vcfsef.org/brochures/index.php](http://www.vcfsef.org/brochures/index.php).

The Knowledge is Hope brochure is currently available in the following languages:

- Arabic
- English
- Italian
- French
- Korean
- Spanish
- Hebrew
- Japanese
VCFSEF AT NORD RALLY IN AUSTIN TEXAS

February 28, 2013 was the National Organization for Rare Disorders International day. Although VCFS/22q11.2 deletion syndrome is the 2nd most common genetic disorder to Down’s syndrome, all individuals impacted by this syndrome can agree that it is “rare” to find professionals who are aware of this syndrome.

A rally on the Capitol steps in Austin, Texas was coordinated by Barbara Hernandez, herself a survivor of Guillan-Barre syndrome, another rare disorder.

Dianne Altuna, and co-worker Kim Krohn participated in this rally. We were joined by several families who have children with VCFS/22q11.2 deletion syndrome. Proclamations were passed in both the Texas House of Representatives and the Texas Senate recognizing February 28, 2013 as “Rare Disease Day and call on all Texans to learn more about this matter of serious concern.”

VCFS/22q11.2 deletion syndrome is one of the rare disorders on the NORD website. For more information go to: http://www.rarediseases.org/

Dianne Altuna and Kim Krohn at Texas State Capitol

DONOR HONOR ROLL
DECEMBER 2012 THROUGH FEBRUARY 2013

FOUNDER ($1000-$4999.99)
Beth Tonet
The Circuit Inc.-Pumpathon Fundraiser
Anonymous

BENEFACTOR ($500-$999.99)
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PATRON ($100-$499.99)
Christine MacDonald
Serena Ritch
Debra Rowold-In honor of Gannon David Wakefield
James and Joyce Mulick

DONORS ($1.00-$99.99)
Laureen Bolding
Karen Spere-In honor of Cheryl Barlow and Tracy Zajac
Matthew Kennedy-In honor of Emma MacDonald’s Small Wonders Daycare
Gail Wright
Rachel Farkas
Dianne Altuna
Deborah Phillips-In honor of Ethan Sims
Nikki Hinnant-In honor of Cayden Helvey
**VCFSEF DONATION FORM**

The Velo-Cardio-Facial Syndrome Educational Foundation, Inc is an organization comprised of both professionals and lay people. Its mission is to educate the public, the scientific community, families and individuals affected by Velo-Cardio-Facial Syndrome (VCFS). Also known as DiGeorge & 22q.11.2 deletion, VCFS is one of the most common genetic syndromes.

Your donation helps support the Foundation's mission and is greatly appreciated. You may also make a donation online at: [http://www.vcfsef.org/support_foundation/donations.html](http://www.vcfsef.org/support_foundation/donations.html)

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VCFSEF, Inc is a US 501(c)(3) non-profit organization. Donations are US tax-deductible to the fullest extent of the law.

Please consider a donation to support our efforts:

**STEP 1: Donation Amount**

- President’s Circle $5,000+
- Founder’s Circle $1,000 - $4,999
- Benefactor $500 - $999
- Patron $100 - $499
- General: $1 - 99

**STEP 2: Select Donation Fund**

- General Donation
  - Educational and awareness materials
- Caitlin Lynch Memorial Fund
  - Provides scholarships for the VCFSEF annual meeting
- Tony Lipson Memorial Fund
  - Helps members from Australia to attend the VCFSEF annual meetings
- Amanda McPherson Fund
  - Supports layout, printing, and distribution of informational brochures in multiple languages
- Kid’s Zone Fund
  - Supports childcare and children's activities for children with VCFS and their siblings during the Annual International Scientific Meeting so that professionals with children and parents may attend sessions.
- Tessa Koller Knowledge is Hope Fund
  - Facilitating Self Competency, Advocacy, Education and Personal Growth for the Journey Through Adulthood.

**STEP 3: Enter Name (if applicable)**

In Honor of:

______________________________________________

In Memory of:

_______________________________________________

My company has a matching gift program:

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**Please include this completed form with your payment made payable to:**

VCFSEF  
P.O. Box 12591  
Dallas, TX 75225

**Total Enclosed $ __________________**
VCFSEF MERCHANDISE

Knowledge Is Hope Bracelets
Promote VCFS awareness by purchasing "Knowledge is Hope" wristbands, available in Adult size (8 1/4") and Child size (7 1/4"). The wristbands are made of 100% silicone and read KNOWLEDGE IS HOPE on the outside of the band, with www.vcfsef.org on the inside.

Each wristband is $1.50 US and shipping is FREE!!! Due to shipping costs, we suggest a minimum order of 5 wristbands for international purchases.

You can purchase your bracelets directly from the foundation’s web site at http://www.vcfsef.org/products/product_list.php

For questions regarding wrist bands, contact wristbands@vcfsef.org, or call 1.855.800.8237

Educational Foundation Logo Tee-Shirts
Promote VCFS awareness by purchasing "Knowledge is Hope" tee-shirts, available in youth sizes S, M, L and adult sizes S, M, L, XL, XXL, XXXL.

The tee-shirts are dark blue and made of 100% cotton, and read KNOWLEDGE IS HOPE, above the VCFSEF logo.

You can purchase your tee-shirts directly from the foundation’s web site at http://www.vcfsef.org/products/product_list.php. Each tee-shirt is $15.00 US, with free shipping in the U.S. and Canada. For orders of 4 or more, shipping outside the U.S. and Canada is also free.

For questions regarding tee shirts, including shipping cost to other destinations, contact tshirts@vcfsef.org, or call 1.855.800.8237

VCFSEF Portfolio
This handy portfolio made its debut at the 19th International Scientific Meeting of the Velo-Cardio-Facail Syndrome Educational Foundation, in Toronto, Ontario, Canada.

You can purchase the portfolio directly from the foundation’s web site at http://www.vcfsef.org/products/product_list.php.
Each portfolio is $10.00 US, with free shipping in the U.S. and Canada.
For questions regarding the portfolio, contact info@vcfsef.org, or call 1.855.800.8237

VCFSEF Magnet
Promote awareness by purchasing "Knowledge is Hope" ribbon magnets. The magnets are 3" x 7" and are 0.030" thick. They are made of vinyl and read KNOWLEDGE IS HOPE and include a modified VCFSEF logo. Lets band together to increase awareness of VCFS (22q11.2) by displaying these magnets on your car, fridge or desk at work. You can purchase the portfolio directly from the foundation’s web site at http://www.vcfsef.org/products/product_list.php.
Each magnet is $10.00 US with free shipping in the U.S. and Canada
For questions regarding the magnet, contact info@vcfsef.org or call 1.855.800.8237
VCFSEF MEMBERSHIP FORM - Become a member today!

Your dues help fund the website, toll-free phone line, education materials, mailings, and our annual international scientific meeting. Donations and dues are the only source of funding for the Foundation. As a member you receive a discount on conference registration and access to the members only section of our website. By becoming a member today, you'll make it possible for the VCFSEF Educational Foundation to move forward—to reach every continent. You may also register online at: http://www.vcfsef.org/support_foundation/memberships.html

New Membership □ Renewal □ Membership dues are payable yearly, and apply to a calendar year, Jan 1 to Dec 31.

First & Last Name: _________________________________________________________________________

Include family members by providing name, relationship, age of child & VCFS diagnosis as applicable:

1. __________________________ 2. __________________________ 3. __________________________

Mailing Address: ___________________________________________________________________________

home       work     Change of address
_____________________________________________________________________________

City                                                        State / Province                  Postal Code                 Country (if not USA)

E-Mail: ____________________________________________________________________________________

Contact Phone: (___________)_____________________________________   Ext:_______________________

Area or Country Code

Full Membership - $40

□ I have Velo-Cardio-Facial Syndrome □ I have a family member with Velo-Cardio-Facial Syndrome
□ I am a professional working with individuals with VCFS. Field __________________________
□ Other:
______________________________________________________________

Dues Total $ ______________________

Request waiver of annual dues for 2010

Student - $20 □

Professional degree student or resident interested in a VCFS related field of study Field: ________________________________

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Tessa Koller Knowledge is Hope Fund

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In Memory of: _________________________________________________________

Please include this completed form with your payment made payable to:

VCFSEF
Attn: Membership
P.O. Box 12591
Dallas, TX 75225

Total Enclosed $ __________

AUTHORIZATION TO RELEASE INFORMATION

I hereby authorize the Educational Foundation to release my contact information as indicated below, to other members and to publish it in a directory for members. The purpose for this permission is to connect people in localities so that support can be offered and information distributed. The Foundation WILL NOT distribute, sell, or otherwise release this information for any other purpose, or for the enhancement of individual doctors or hospitals. You may release my: □ Name    □ Address     □ Phone #    □ Email address     □ Release NONE


DISCLAIMER

The information contained in this newsletter is for informational purposes only, and should not be used to replace professional medical advice. Readers are responsible for how they chose to utilize this content. This information should not be considered complete, nor should it be relied on in diagnosing or treating a medical condition. It is best to seek advice and attention from your physician or qualified healthcare professional. Always consult your physician before beginning a new treatment, diet or fitness program.

CONTACT INFORMATION

If you have further questions, including membership in our organization, please contact The Foundation via phone, post, or email, and we will assist you.

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Toll Free 1.855.800.VCFS (1.855.800.8237)
Local Number 1.214.360.4740

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Dallas, TX 75225

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