



The Virtual Center for VCFS

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Issue 04

VCFS News: Your Information Resource

In this issue:

Page 4: Family Response and Management When Someone Has VCFS
A Q&A Session with Jocelyne Gardner, M.S.W., L.C.S.W.

Page 2: Where is the World is Ray?

Page 8: Daniel, Who Likes to Jump Out of Airplanes (With a Parachute)

Announcements: Jocelyne Gardner joining our staff of Experts (page 4)

and Establishing Peer Groups (see below)

ANNOUNCEMENT REGARDING PEER GROUP FORMATION

We are so excited about the wonderful response we have had from so many of our registrants to join the peer groups that we are forming! We are working to get everything organized and we will reach out to everyone that has contacted us soon. Please be aware that it will take a few weeks as our director of peer groups, Raymond Cheng, is about to embark on a wonderful trip to Asia but he has already started working on the groups and is going to be reaching out to everyone that has emailed us. If you or your child is interested in participating in the peer groups, please email jodi.bloom@vcfscenter.org with the participant's name, age, city that they live in and interests/hobbies so we can make sure to connect them with their peers.

Jodi Bloom, jodi.bloom@vcfscenter.org or jodi.bloom@vcfscenter.com



The Virtual Center for VCFS

Where in the World is Ray?

There is something amazing about traveling. Seeing the world, creating memories, whether it be solo or with friends, it can give an excitement and exhilaration like no other. As someone with VCFS, I understand that it is a struggle and how hard it is for others to be in a different environment, especially if it is halfway across the world. Last year, I solo travelled for the first time in Amsterdam, then in Iceland, and while initially I was terrified and wondered what on earth I was doing, I found myself loving it. It was something I've never felt before, to be able to walk around, sightsee, enjoy at your own pace without a care or worry in the world. And while it was scary at times (like getting lost with no one around and my phone battery dying), I found myself realizing that is all part of a learning experience and found myself loving it again shortly after. It really is a tremendous way to grow your character, I think, to be able to travel on your own, to face the fear.

I will be leaving soon for Singapore and Thailand and when I return, I would like to show you what that part of the world looks like. I will be away for two weeks with three of my guy friends. It will be the first time I will be travelling in a group like this, and I am excited (except for the 24-hour flight, ugh). I'll also be taking some incredible pictures of sunsets, food, temples, and so much more. From the Wat Arun Temple to the Gardens by the Bay, I can't wait to show you what's in store.

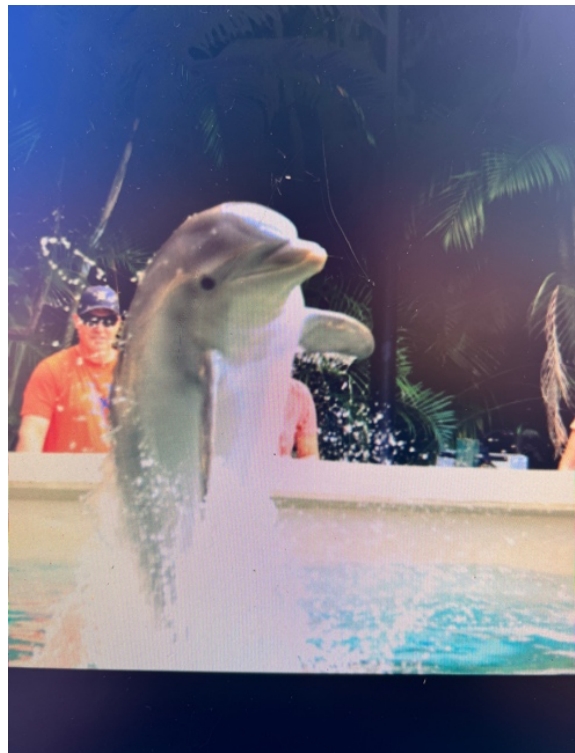
Your Editor, Ray Cheng



Our Monthly Art Pieces

Courtesy of Laura Smith

Laura Smith enjoys multiple forms of art, including photography and character design. Here are three examples of her work. Laura lives independently in the Orlando, Florida area and currently works at Sea World in Orlando.



A Q&A Session with Jocelyne Gardner, M.S.W., L.C.S.W.

Clinical Social Worker/Therapist

Newest member of our team of experts with a focus on families of people with VCFS

Jocelyne Gardner is a psychotherapist, licensed clinical social worker, and she is also a parent of a 22-year-old son with VCFS. She will be joining our team of experts bringing an emphasis on family dynamics. She will be available to our registrants to offer insights as how families can manage the challenges facing parents and siblings, as well as extended family when a child, adolescent, or adult has VCFS that can create medical and behavioral challenges that may disrupt family life and family interactions. Jocelyne has more than 18-years of experience as a clinical social worker with an additional two-year post-graduate clinical fellowship with a specialization in psycho-dynamically oriented child, adolescent, and family therapy as well as intensive professional training in collaborative therapy with couples. Prior to opening her private practice, Jocelyne worked in a variety of settings including medical social work, early childhood education and special needs consulting, community mental health, crisis counseling, family therapy with medically fragile infants, led parent workshops, facilitated bereavement and parent support groups.



Jocelyne has worked, trained, lectured, and consulted in a wide range of settings including The Ann Martin Center, Kaiser Permanente, Through the Looking Glass, Contra Costa Crisis Center, Pathways4Parents, Jewish Family and Community Services, Jewish Federation of the East Bay, Children's Hospital Oakland, Women's Cancer Resource Center and is a volunteer ambassador for Sharsheret.



Advice and Strategies from Jocelyne Gardner

Our Newest Expert Available to our Registrants

The diagnosis of VCFS can be overwhelming for some parents. What advice can you give to them to create an atmosphere that will allow the family and the child with VCFS to thrive?

I have the unique perspective of being a parent of a 22-year-old son with VCFS and a psychotherapist that specializes in supporting other parents of neurodiverse children. I vividly remember the moment when the doctors told us about our 5-day-old son's diagnosis. We were shocked, overwhelmed, and scared. We had no idea what it meant for our baby's future and what it would mean for our family. When our son was about 2 years old, I decided to go back to graduate school with the goal of supporting other families going through similar experiences and I currently work with parents in my private practice. Our family has come a long way over the years, and we have learned so much about what it means to have a child born with a genetic disorder. Although every family processes their child's diagnosis differently, the following is what I have learned through both personal and professional experiences:

- **Take a deep breath and slow down.** It's easy to panic prompting you to go online to read everything you can about VCFS. That can be incredibly overwhelming and scary. VCFS comes with a wide range of medical, emotional, and learning challenges and not all of these will apply to your child. For example, when our son was born a doctor told us that he might never walk or talk. I'm sure you can imagine how devastating that was to hear. However, this doctor couldn't have been more wrong! Our son walks and talks just fine, and that prediction was so far off base from his reality that it's almost laughable now.
- **Share the diagnosis with your inner circle of friends and family.** At first, we didn't tell anyone other than our parents. We feared judgment or pity from others if they knew and we wanted to avoid potential shame for ourselves. We felt protective over our son. However, what we quickly learned is that keeping such a big secret leads to isolation, loneliness, and depression. After speaking with a therapist at the time, I realized that we needed to share our son's diagnosis with our close friends and once we did that, the outpouring of love and support was beautiful and very healing for my husband and me. People want to help and offer support if you let them.
- **Develop a quick 'elevator pitch'** (a quick 30 second way of sharing information, roughly the amount of time it takes to ride in an elevator with someone) when speaking with others who you don't know well, don't feel comfortable with or if you aren't in the mood to discuss your child's diagnosis. For example, I quickly learned that if I said "My son was born with a genetic disorder" then this would lead to unwanted questions, and I'd feel pressured to share more than I was comfortable with discussing. Eventually, I learned to deflect questions when I wasn't in the mood to elaborate by saying "it's complicated, I'll tell you another time" or "long story...". Most people will get the message and respect this boundary.
- **Given all the potential challenges a person with VCFS will face in their lifetime it's critical to preserve and boost their self-esteem at every opportunity.** We quickly became our son's biggest advocates and cheerleaders. We praised everything he did and cheered on his every accomplishment. First crawl, first smile, first bite of solid food, first step...everything. No matter how difficult it might be to get there, celebrate it loud and proud!
- **Take advantage of all services available starting as soon as possible.** Speech therapy, occupational therapy, feeding therapy, social skills groups, play therapy, IEP school support, regional center...do it all if it is needed and keep an eye on your child's progress. It takes time, research and even being in the right place at the right time to find the specialists who understand this syndrome. If you don't see positive progress within a few months, it might not be a reflection on your child's abilities and instead could indicate that you need to work with someone else. For example, our son had speech therapy for years and made very little progress. It wasn't until he saw a new speech therapist as a teen and she suggested that there might be an issue with his palate which prevented him from speaking clearly that no amount of speech therapy could fix. This led to further investigation and doctor's appointments which ultimately led to surgery to fix the issue. Trust your instincts and I encourage you to consult with the VCFS Virtual Center for another opinion. Early support and intervention will help make a huge difference in your child's development.
- **It's important to recognize that your goals and priorities for your child might need to shift.** For example, before having a son with VCFS I assumed my child would someday attend a traditional four-year college. However, over the years I came to realize that there are many different paths our kids can follow, and college is only one of them. In our case, our son

graduated from high school, is attending a transitional program learning to live independently, completing a culinary arts program and works at a Michelin star restaurant. You will need to reimagine what your child's life and future will look like. This takes time. Individual therapy, couples therapy and support groups can help you process your own grief, worries or disappointment that life for your child will look different than planned and help you adjust to your "new normal." Although your hopes and dreams for your child will change, they are still going to do incredible things in their life, it just might look different than what you planned on.

- **Find a good therapist.** Having a child with unexpected challenges is stressful and it's important to put the work in to keep yourself and/or your partnership strong and steady.
- **Find a support group for parents of neurodivergent children.** You will learn a lot from other parents, connect with others who truly understand what you are going through, and you will potentially make new friends that 'get it' in a way that others do not.

How can we teach a sibling of someone with VCFS to best understand and accept their brother or sister?

It is important that the sibling(s) of someone with VCFS receives just as much attention in the family. Allow siblings to have alone time or special activities just with you.

- Don't ask or expect the neurotypical sibling to always be "good," a role model, well-behaved, helpful, high achieving or understanding. Give them room to just be themselves.
- Support and honor your other children by recognizing that having a brother or sister with special needs can be embarrassing or frustrating and they might feel confused, ashamed, or guilty for feeling this way.
- It can be helpful for your other children to have their own therapist to talk privately with occasionally.

Many children who are diagnosed with VCFS need to undergo surgery, sometimes multiple operations, such as cleft palate and heart surgery. What can you recommend for easing anxiety in the child and family members?

- Every single parent is anxious when their child has surgery. I don't think this can be avoided. However, finding the right team of doctors can certainly help ease your fears. In our case, our son had laryngeal web surgery a few hours after birth, multiple ear tube and hernia operations as a toddler. As a teenager he had a palatal lengthening procedure that made his nasality more severe rather than eliminating it. This bad outcome led us to reach out to Dr. Shprintzen at The Virtual Center for VCFS. We worked with his team of experts who recommended a different operation. We trusted their guidance and our son had another procedure to resolve this problem and it was successful. Dr. Shprintzen and his staff are the world's leading experts on this genetic disorder. Reach out and ask for guidance. Knowing you have their intelligent and caring team to support you will go a long way in helping you feel confident that you are making the right decisions for your child.

The issue of what the future holds (school, career, friendships, and romantic relationships) is of importance to the families of people with VCFS. Are there suggestions about the handling of this uncertainty?

- **Try and stay in the moment.** It's easy to let your mind spin out of control, thinking about the future and what it will look like. However, nobody can predict what the future holds and how your child will develop and change over time or even what medical advances might be discovered. For example, our son was underweight as an infant, had trouble swallowing and had

to work with a feeding specialist for months. Now at age 22, he's a 'foodie', loves to cook and we can't believe how much he eats! We also couldn't envision if he would graduate from high school, go to college or what his future career might look like. Today he's living with a roommate in an apartment, attending an independent living program, completing a culinary arts certificate, and working at a restaurant. Most importantly, he's happy! Take things one year at a time and focus on the present rather than what is unknown or unpredictable in the future.

What advice would you recommend to parents of a younger child with VCFS in terms of establishing friendships?

- Invite other children over for playdates.
- Invite the entire class for birthday parties.
- Enroll in camps, classes and after school programs for neurodiverse kids.
- Find a social skills teacher or social skills group for your child.
- Notice which teacher or counselor is great with your child and ask if they'd like a job babysitting, tutoring, or taking them out on fun outings.
- Allow your child to play multiplayer video games such as Minecraft, Roblox, Mario Kart, Star Stable or Just Dance so they can play with friends virtually vs in-person. By doing this they are working on their social and communication skills in a low-stress and fun environment.
- Before a playdate, practice role playing with your child on how to talk, play and share with other kids.
- Write up a brief synopsis for teachers at the beginning of the school year as an introduction to your child, what their challenges and strengths are. Teachers really appreciate this extra guidance in understanding and knowing how to best support your child academically or socially.

The social challenges that teenagers face in general are difficult for all adolescents. How should these issues be faced in teens with VCFS?

- A social skills coach or group is very helpful in teaching a teenager with social challenges how to engage in small talk, read social cues, interpret body language and how to join in or initiate chatting with peers.
- Help your teenager get a part time job that provides opportunities to talk with others. For example, the fast pace at Starbucks might be too intense, however, working at a grocery store, clothing store or a movie theater is a good first job for someone with social challenges and anxiety. It allows them to practice their social skills in a less stressful environment.
- Helping your teen find outings and activities (through a club, camp, sport, gym, after school program, a religious organization or house of worship, volunteer organization) is a relatively low-stress way for them to socialize. This avoids the pressure and stress of having to initiate and organize a social activity...your teenager just needs to show up.
- Don't expect your teen to do every outing or social activity that the rest of your family is doing. Respect and allow them to stay home or retreat to their room if a social situation is potentially too overwhelming for them.
- Lastly, you might have been a popular and social teenager but that doesn't necessarily mean that your socially anxious teenager is unhappy or lonely. Be careful not to project your experiences, worries and fears onto your child. They might be perfectly happy the way they are.

Finally, I am so happy to be joining the team at the Virtual Center for Velo-Cardio-Facial Syndrome. I look forward to providing advice that may be helpful to our registrants. Having been at the receiving end of this amazing team years ago, becoming a part of it at the giving end of the equation is a truly profound privilege.

Our Friend Daniel Who Jumps Out of Airplanes *for Fun!*

My name is Daniel, and I am from Houston, Texas. I was diagnosed with VCFS at approximately six years of age. I've had two submucous cleft palate surgeries, lots of doctor visits and many speech therapy and occupational therapy sessions growing up and have some learning problems as well. However, I was still able to overcome these problems and have had many successes in my life. I got my driver's license at age 16. I was able to pass the GED test first try and then passed the entrance test to get into community college. Once I had enough



credits with passing grades, I was able to transfer to a university without ever having to take the SAT! It took me six years, but I was able to graduate with a Bachelor of Science degree. I have been working full time ever since for companies like Tesla as a production associate and IBM as an IT field technician for several years. I am now an IT technician in a corporate office. Some of my hobbies include skiing, traveling, and skydiving. Growing up, our family would travel to the Lake Tahoe area almost every winter to ski. Believe it or not, I have even gone down a black diamond trail. I enjoy solo traveling all over the world. I have been to 5 continents, 15 countries and many states. I spent 6 weeks in Northern Iraq in 2012 and a mission trip to Mozambique in Africa. From my first try, I have enjoyed skydiving, jumping out of a plane at 14,000 feet. I have made more than 200 skydives.



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