

VCFS News: Your Information Resource

This Time of Year



Art work 1: Courtesy of the artist, Jordyn Thornton of Henderson, Nevada, USA

This time of year, from late November through February, has always been a bit of a puzzlement. If we pay attention to television commercials, newspaper advertisements, radio station music, and movies in theatres and on television, we would all think that this is the biggest, happiest, whiz-bang time of year when we are joyous, families are together laughing and toasting each other with favorite beverages, eating special foods for the season based on our individual cultures, and singing songs of faith, happiness, and childhood themes, and of course, gift-giving and delighted children with smiles on their faces and expressions of delighted surprise as they unwrap gigantic boxes. That being said, for people suffering with anxiety, there is a lot of tumultuous activity going on with people coming and going, dinner tables with noise and everyone talking at once, too many choices to make at the dinner table, and possible disappointments with the gift you got because you had your heart set on something else. For

people with VCFS, the season can be difficult in large part because it is different than the routine comfortable life they had just before the holidays. They may also be surrounded with people they don't know. In this edition, our Psychology Expert, Bronwyn Glaser, Ph.D., addresses questions we often receive related to the season. It doesn't matter if we are talking about Christmas, Chanukah, Kwanzaa, Thanksgiving, New Year's Eve, Chinese New Year, and we can even stretch this out and apply it to Easter, Passover, Ramadan and Eid al-Fitr, Diwali, Holi, etc. All special days are disruptions in the usual days and the set patterns of life that we have. The pressure of these days can affect anyone, but the effect is felt moreso in people who have VCFS. Our Editorial Board decided that this would be a good time to have Dr. Glaser, our expert in the field of psychology, offer some suggestions and observations. Dr. Glaser has studied and treated people with VCFS for more than two decades and has been the author of many articles and book chapters, a frequent lecturer internationally, and a developer of the computer

app Vis-à-Vis. I have also asked our Newsletter Editor, Raymond Cheng to describe his own personal view of the season, which follows this introduction.

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This Time of Year for A Person with VCFS

The holiday season is an exciting time for most people, with children and adults unwrapping Christmas presents, Secret Santa games, family and friend gatherings going into the New Year. With the New Year, fireworks are heard for many days in a row and champagne glasses clink in celebration. However, for some people, it is a time that we do not look forward to, and we often dread when it is around the corner. This is because while others are enjoying the celebration and brouhaha, we often feel fear and anxiety. Although many people have anxiety as the holidays approach, it escalates more vividly for people with VCFS. For someone like me, the anxiety heightens tremendously. I try my best to make small talk and engage in conversation, but soon uneasiness and fear overcome me so that I just want to go home or do my own thing. If others, do not understand or know the syndrome well, this can cause problems. They might ask, “Why isn’t he participating?” or “Why is he being so weird and quiet?” It’s hurtful and it harms us even more. Most of the time we don’t have the energy or time to explain to strangers what VCFS is and why it affects us; we simply want to isolate.

It is frustrating, but if others understand what I have, it makes life easier. Fortunately, my family knows the ups and downs of this syndrome and whenever the stimulation gets too much, they adjust accordingly, for which I am grateful. When strangers are involved, I do tend to abstain from these types of celebration. Participation might be fun and make for great memories and stories to tell, but sometimes they are simply too much. Recently, during a Thanksgiving dinner, even when it was with family, there were too many of us in the room and I just wanted to go home. But I did not want to disrupt the happy times or make it about me and decided to stay. And sometimes, when we are playing board games or Secret Santa, I will not understand the rules of the game, and it will frustrate others because they will have to repeatedly explain the rules, thus disrupting the flow of the game. It is exasperating and disheartening to see others (especially those who do not understand the syndrome) to roll their eyes or sigh in impatience. That’s why it is so important to be with those who understand and love you for who you are, to be patient enough to accompany your needs. It is the holiday season, after all, and it is everyone’s wish for good vibes and happy times around us.

Raymond Cheng
Director of Peer Relations
Newsletter Editor

Making the Best of the Holiday Season

Insights from Bronwyn Glaser, Ph.D.



Psychology Expert for the Virtual Center for Velo-Cardio-Facial Syndrome

1. **As the holidays approach, what can someone with VCFS do to cope with the large crowds/unfamiliar surroundings and the anxiety it causes?**

It can be helpful to prepare for crowded events. It is important to talk to your child about what he/she can expect and familiarize him/her with the details of the plan. For younger individuals, it is important to have something quiet to do to entertain themselves if they get bored or just need some quiet time.

For adults, it can be a good idea to go for just a limited amount of time or to attend with someone. Look at the schedule and check if it is possible to shorten the evening or duck out for some air. In addition to knowing what to expect, it is also important to prepare some conversation starters. I encourage teenagers and adults to think ahead of time of topics that make good small talk and may be of interest to others at the event. It is often useful to roleplay these conversations ahead of time with a parent, friend or therapist. Individuals with VCFS can worry about not having enough to say and will feel calmer when they have a few prepared ideas in their pockets. Individuals with the syndrome still prefer to be included in gatherings, they just need to know what to expect and where to go when they need a break.

2. **I have read that exposure theory can help with feelings of fear and anxiety of large crowds/unfamiliar surroundings. Is that true for people with VCFS?**

Most behavioral therapy programs targeting fear do include some component of exposure therapy. The therapist will help the client to prepare for the situation and then ease him/her into it in a controlled and gradual way. The most important part is to make sure that the exposure is very gradual so that the person feels successful, but not threatened.

In the case of parties or crowds, the social demands can often be the scariest part for individuals with VCFS. If someone is tackling a crowded party, it is a good idea to first become comfortable in a smaller-scale setting; and then ease into larger settings by either having a role that allows him/her to stay busy during the event, or by attending with someone who can be their social “co-pilot” and assist during group conversations.

3. **Are Cognitive Behavioral Therapy (CBT) and hypnotherapy good choices to help with fear and anxiety of large crowds/unfamiliar settings in people with VCFS?**

Yes, both have been shown to be useful, but there is no “one-size fits all” solution for everyone. Living with chronic anxiety can make people feel both vulnerable and powerless. It is very important to help individuals to understand reactions that are triggered by stress or anxiety.

Most CBT programs for anxiety try and help clients to externalize or separate out anxious feelings, sometimes by thinking about them as a “dictator” or an “interloper”, to understand reactions that are induced by the anxiety. The goal is then to make the “dictator” powerless by realizing that it can induce a very real sense of danger when danger is not actually present. Dr. Anbar, our expert hypnotherapist, can better explain how hypnotherapy works.

4. How can people with VCFS engage in conversation with other people at a social event?

In social skills groups for VCFS, we practice asking questions and initiating conversations. Both are skills that can be difficult for people with VCFS, due to reduced working memory and the presence of social anxiety. Individuals with the syndrome will often say that they can't think of things to say, especially in group situations. Again, I would prepare some topics of conversation ahead of time and practice asking questions. Asking questions is a magical skill because the person answering then answers, taking some of the burden off the question asker. It can also be helpful to remind individuals that they do not need to engage in long conversations. They can simply look a person in the eye and give an appropriate greeting, which on its own, is friendly behavior at a holiday gathering.

5. If someone with VCFS is traveling for the holidays, what can they do to minimize their anxiety?

A lot of individuals with VCFS really enjoy traveling but can become overwhelmed when preparing for a trip. Again, it can be very helpful to map out the travel. A week before leaving, sit down with the individual and make a list of what to pack and a separate list of activities for the car or the plane ride. Post this list in a place where the person can easily refer to it. If they start to become anxious about not having everything, you can refer them to the posted list so that they add to it as needed.

I also find that individuals with the syndrome tend to underestimate the time that trips take and feel confused by when certain things will happen. This is supported by research on temporal perception in the syndrome. I would say that it is good to map out the different phases of the trip. For young children, the trip can be represented using cartoon sequences to break it into smaller parts so they know when the breaks or meals will come and when they will have time to do certain activities while they wait.

Lastly, individuals with VCFS often persevere when they are looking forward to things. Instead of a parent answering the same question over and over, a posted calendar with the travel date clearly marked allows the child (on their own) to count the days that remain. Accessing the information on his/her own builds important autonomy.

6. Should medication be used by people with VCFS to minimize anxiety during a party or a family or social gathering?

There is not a universal answer to that question. Some individuals with VCFS do benefit from being treated for anxiety and it is worth discussing medication possibilities with a treating psychiatrist, especially if behavioral fixes are not working.

7. What can parents of a child with VCFS do to relieve their anxiety when they are with a lot of people?

In addition to the above suggestions, I would recommend planning out the evening with the child and telling them clearly when they can take some time for him/herself. Make sure they have activities with them (something they like to do on their own). It is also important to tell the child if there are times when they should not interrupt their parents, so that they understand what is expected during the event.

8. What should a parent of a child with VCFS not do with their child during the holidays?

The most important part is to pay attention to your child's specific fears and find a solution that works for him/her. For individuals with VCFS, it is very important to avoid situations that trigger stress reactions, but what will be stressful for your child is individual. Some children are afraid of sleeping in the dark, especially in a new place without someone else in the room, others are afraid of interacting with people they don't know and so they stay very close to their parents or caregivers during big gatherings. Consider your child and his/her reactions and plan ahead to reduce the overall stress of the situation.

9. What can siblings of someone with VCFS do to ease their anxiety and what should siblings NOT do during the holidays?

Siblings and cousins that are close in age can be a great source of comfort. If there is a big group gathering, the same preparation is useful for siblings so that they take care to include the child with VCFS in their activities. At the same time, it is important that the sibling role doesn't become onerous. I would encourage parents to check-in with siblings to see when a sibling needs some personal space or a separate time with their parents. Due to the ubiquitous anxiety in the syndrome, siblings can often feel like the affected child is glued to their parents' sides, making it hard to find their own place in the family. For this reason, it is important to help a sibling to identify his/her own needs so that resentment does not build up around the affected child.

10. If a person with VCFS is too nervous around large crowds/big gatherings, should they just isolate or stay home?

Just like for anyone, it is important that individuals with VCFS think about what will bring them joy and rest during the holidays. It is good to balance time spent in big and small groups and choose the activities that bring joy. We cannot do everything, and so one big challenge during these busy weeks is how to balance time spent celebrating and time spent feeling normal at home.

11. What are some fun and safe activities for someone with VCFS during the holiday season and what should someone with VCFS NOT do during the holiday season?

For important neurological reasons, it is especially important for individuals with VCFS not to abuse drugs and alcohol. We often see young adults who self-medicate with alcohol or marijuana to tolerate the inherent stress of social situations. I would encourage people to adjust the social setting to avoid the need for vices.

Similarly, for children, it is important to avoid stressful triggers (i.e. really scary movies or stories, forcing kids to sleep on their own in new places or pushing them to do something that is too far out of their comfort zone). Reading a story together and watching the child's reaction can be a good way of understanding their tolerance to stories. Reading stories tends to be less threatening than the visual images that are left by movies or scary TV shows.

12. **How long before the holidays should a child with VCFS be prepared for the holidays?**

This is an important question. We don't want to prepare so far in advance that we induce obsessive thinking about what is to come, but we do want to go into the season fully prepared. I think a paper calendar (gasp!) at home can really help put everyone on the same page. It allows us to mark not only major events, but also free time, so that children see that there is a balance in the weeks to come. Start by planning ahead with your child about how involved he/she would like to be in each activity.

Individuals with VCFS are usually very socially motivated and enjoy being involved in family and community events, they just need reassurance and comfort. Make sure that any social expectations are clearly stated and not implied (i.e. gift giving) and that the focus of the events is not on the child, but rather, on the spirit of the season and on helping those around us.

SPECIAL ANNOUNCEMENT



We are very pleased and very proud to announce that our Speech Expert, Dr. Karen J. Golding-Kushner was awarded two major honors by the American Speech-Language Hearing Association, the professional organization that serves more than 225,000 professionals worldwide. From this huge membership, only one person every year is awarded the Frank R. Kleffner Lifetime Clinical Career Award. Dr. Golding-Kushner was the recipient of that award for 2023, a remarkable achievement. She was also awarded the Certificate of Recognition for Outstanding Contributions in Clinical Achievement by ASHA at the annual convention in Boston last month. The announcement of these high honors from one of the largest professional organizations in the world as posted on the ASHA web site reads as follows:

Karen Golding-Kushner is honored for more than 40 years of service and contributions. Her clinical career has been dedicated to advancing clinical treatments for patients across the lifespan with cleft lip and/or cleft palate and associated craniofacial syndromes.

Her seminal textbook, "Therapy Techniques for Cleft Palate Speech and Related Disorders," has been an influential resource for students and practicing clinicians. Throughout her career, she has provided leadership to the Velo-Cardio-Facial Syndrome (VCFS) Educational Foundation and to the Virtual Center for VCFS to support professionals and families. She was one of the first clinicians to

provide telehealth speech services for patients with cleft palate and associated disorders and has served as an expert in telehealth delivery. Since 1980, her private practice has specialized in treatment for patients with cleft palate and craniofacial disorders and syndromes. Golding-Kushner's lifetime of service has been devoted to advocating for and improving outcomes for children and families affected by communication disorders around the world.

It should be mentioned that Dr. Golding-Kushner's contributions also include a seminal book regarding speech therapy in people with VCFS, ***Velo-Cardio-Facial Syndrome, Volume II*** published by Plural Publishing that contains video examples of therapy techniques from infancy through childhood to adult life that has helped many of the registrants to the Virtual Center. She is a true giant in her field and we are so very fortunate to have her talents to offer our registrants.

The Virtual Center for Velo-Cardio-Facial Syndrome

