The Virtual Center for VCFS

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## In This Issue



**Peer Groups: Making Friends Near and Far**
**Raymond Cheng**



**More Than a Peer Group: Finding Joy, Connection, and Friendship Through the VCFS Peer Groups,**
**Jodi M. Bloom,**
**Director of Community Relations and Director of Development**

***Artwork from the talented hands of Chesney Reynolds from Tennessee***



**Welcome to a new expert at the Virtual Center, Dr. George Cisneros, D.M.D!**

To our readers: If there are any topics that you would like to see discussed in our pages, please contact our Editor, Raymond Cheng at raymond.cheng@vcfscenter.org, or jodi.bloom@vcfscenter.org, or call Jodi Bloom at 315-949-4818.

# Peer Group Update

**Raymond Cheng, Director of Peer Groups**

**Quotes from participants in the Peer Groups**

*"I really enjoy connecting with everyone from different backgrounds and cities. It makes my day knowing people are out there with the same thing I have. I enjoy sharing my thoughts with people who share my hobbies and encourage me to find a job. Because with the right support I know I can be independent and social."*

*"There is no 'I' in the word peer. Peer groups are made up of a community, a community where we can joke, laugh and just have fun together. We work together. These peer groups give me an opportunity to socialize and laugh once a week. It lets me know I'm not alone in dealing with this."*

*"It has been a really positive experience for my daughter. It's helped her connect with other people who have the same syndrome, and she especially enjoys playing games and visiting with everyone. Recently, she's even started joining more than one group, and she really looks forward to it, especially when her friend is able to join and they can participate together."*

*"I like how these meetings are open to everyone, and that everyone gets included"*

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Hello everyone! My name is Ray Cheng. I am the Director of the Virtual Center for VCFS Peer Groups. Our peer groups meet virtually online allowing participants to spend time with their friends and play games. The quotes above are from some of our peer group participants as well as the parent of a participant all of whom love being a part of them. We have had two highly successful years and I am excited to share that we have added additional groups to accommodate the high demand:

Wednesday from 5-6pm EST
Thursday from 5-6pm EST
Friday from 4-5pm EST
Sunday from 4-5pm EST

We have grown steadily over the past two years, and word has gotten out that our participants get together purely to have fun. We receive calls and emails from all over the country asking to join. I love seeing everyone participate and having fun, and some of the participants have even exchanged numbers to chat outside of the groups, which is so heartwarming to me. The sole purpose of the groups is to make friends and socialize and to play games like Hangman and Jeopardy, and it is becoming increasingly successful as time goes on.

One thing I like most about the peer groups is how excited the participants are to see each other every week. They are always so excited to play the games, too. I love seeing them work together to try and answer questions in the games. I also smile seeing them so happy, feeling pride when they get the answers correct. I try to change the level of difficulty as well, to try and get them to use their brains and work together as a team. For example, every week I choose a different category for Hangman. One time, I chose "space" as the category and put in some tough words like "supernova" and "Milky Way." To my surprise, one of the participants got it right away, leaving her smiling and, I think, full of satisfaction. We also play games like Kahoot and UNO; it depends on what they feel like playing that day.

There is also so much to talk about, especially everyone's hobbies and interests. Everyone has such interesting lives, and I love learning about everyone, their hobbies, what their hometown is like, and what they like to do

during their down time. For example, we recently got a participant from Wisconsin, who I had befriended, and he is in the Sunday groups. From my conversations with him in the peer group and through text messages, I learned that he loves trains, and he shows me towns and places I've never heard of (I recently took the Amtrak to Connecticut and shared a video of the train with him; it made me smile that he loved it). And as someone who's lived in New York City for over ten years and never stepped foot in Wisconsin (or anywhere in the Midwest), I am in awe at how vast and diverse our country is. We have someone from Louisiana; she recently traveled to Jamaica with her husband.

Another thing I love about the peer groups is how diverse the participants are. For example, today I hosted a group that had five participants: one from Kansas, another from Louisiana, another from Texas, another from Wisconsin and another from upstate New York. All around the country, with different lives, yet coming together to just have fun. One of the rules of the peer groups is that we do not talk about VCFS. We may all have it, but we do not talk about health issues, challenges, etc. We just get together to have fun. That's what makes these groups so special: They are NOT a support group. There is an unspoken harmony between the participants. I'm there to make sure everything flows smoothly.

These groups are also designed to showcase our registrants' talents and accomplishments. Our participants are unbelievably talented. We have one young woman who lives in Tennessee; she specializes in gemstone painting, something I have never heard of before, and am blown away by her creations. Her artwork is shown in this issue of the Newsletter. Another registrant lives in Utah. Her drawings could be displayed in a museum. One participant that lives in Florida for part of the year and in Colorado for part of the year runs a camp. A long-time participant just graduated from a college honors program and we all celebrated her success. We also show off our pets and enjoy together how cute they are (although my dog would love to just sleep, I have to show him off).
As someone who has VCFS, I understand how difficult it is to make friends and socialize with the outside world. It is scary. But everyone who has joined the peer groups have been so welcoming and so extraordinary; it makes me emotional at how much it has grown.

If you would like to join a group, please reach out to me at raymond.cheng@vcfscenter.org, or contact me by phone at 917-370-7627. I will set up an introductory meeting with you, and I will be asking about your hobbies, if you have registered with the Virtual Center, and simply get to know you before placing you in a group. If you have any questions or concerns, you may reach out to me.
We look forward to seeing you in one of our successful peer groups soon!

Ray Cheng

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# More Than a Peer Group: Finding Joy, Connection, and Friendship Through the VCFS Peer Groups

**Jodi Bloom, Director of Development and Community Relations, jodi.bloom@vcfscenter.org**

For many people with VCFS, opportunities to connect with others who share their experiences can be limited. While support groups and educational programs can provide an important place to talk about health, challenges, and daily life, there is another kind of connection that is just as important: **the opportunity to simply have fun together and make friends.**

That is the heart of the Virtual Center for VCFS Peer Groups.

The peer groups, led by Director of Peer Groups for the Virtual Center for VCFS Raymond Cheng, have become a tremendous success by creating something intentionally different. These groups are a positive, welcoming environment where participants come together with their peers—but **VCFS is not the focus.** In fact, participants are asked not to discuss their diagnosis, medical conditions, or the syndrome's problems during the group.

Instead, we talk about the things that make life enjoyable.

We talk about hobbies and interests. We share stories about travel, favorite foods, movies, music, pets, holidays, and the things we are excited about and things we would like to share. Participants have the opportunity to discover what they have in common with one another and, just as importantly, to discover new interests and perspectives from their peers.

And, of course, we have fun!

Games are a regular part of our gatherings. Whether we're playing Hangman, Jeopardy, Kahoot, or another game, participants get to laugh, compete, cheer each other on, and exercise their minds at the same time. These activities create opportunities for everyone to participate, regardless of whether they are talking about a particular interest or simply enjoying the moment.

**A Place to Be Yourself**

One of the most meaningful aspects of the peer groups is the opportunity to spend time with people who understand what it is like to live with VCFS—without having to talk about VCFS. That distinction is important. There is nothing clinical about the sessions that fill a need for the ability to socialize with people who will not be judgmental, will not be dismissive, and who will look forward to seeing you again.

Our director Raymond also has VCFS and that is one of the most important factors of what makes these peer groups so successful: Ray speaks from experience and he knows what it is like to live with VCFS so this makes him exceptionally qualified to lead our peer groups. Ray has done a tremendous job of getting to know our participants, leading active and engaging groups and becoming a mentor and friend to everyone that joins. Ray often contacts some of his new friends outside of scheduled meetings just to see how they are doing, or to discuss something that was the subject of a previous meeting.

Participants don't have to explain their diagnosis. They don't discuss medical appointments or health concerns. They don't spend their time talking about challenges. They can simply show up as themselves.

For some participants, the peer group has become a place where friendships have developed outside of the scheduled meetings and where they look forward to seeing familiar faces. For others, it has provided an opportunity to meet people they might never otherwise have had the chance to know.

In a world where people with VCFS may sometimes feel isolated from their peers, having a regular opportunity to laugh, socialize, play games, and share interests can be incredibly meaningful.

**The Ripple Effect**

Although the peer groups are **not designed to be therapeutic or support groups**, participants and their families have shared encouraging observations about the impact of participating. Many participants report feeling happier after becoming involved in the groups. Families have also told us that they have noticed positive changes, including decreased anxiety and greater happiness. These reports are not the purpose of the peer groups, and we do not present them as a substitute for professional mental health care. Rather, they illustrate

something that we have seen repeatedly: **having meaningful social connections and opportunities for enjoyment can matter.**

Sometimes, a person doesn't need another conversation about what is difficult.

Sometimes, they need to laugh.

Sometimes, they need to win a game of Jeopardy.

Sometimes, they need to discover that someone else loves the same food, movie, hobby, or travel destination.

And sometimes, they simply need to spend time with people who "get" them.

**Making Room for Joy**

The success of the VCFS Peer Groups reminds us that quality of life is about more than managing challenges. It is also about making room for friendship, laughter, curiosity, and fun. Our participants come together not because they have to talk about VCFS, but because they have an opportunity to **enjoy being together.** That may sound simple—but the impact can be anything but simple.

The peer groups provide a much-needed opportunity for people with VCFS to connect with their peers, build relationships, stimulate their minds, share their interests, avoid isolation, and, most importantly, have fun.

Because sometimes the most meaningful connection happens when we get together just to have fun, enjoy each other's company and just be with other people without having anxiety induced by shyness or being intimidated.

**If you speak to others who might have questions about the peer groups, you can provide the following responses to them**

**What is a VCFS Peer Group?**

The VCFS Peer Groups are virtual gatherings where people with VCFS can connect with their peers in a fun, positive, and social environment. The focus is on friendship, shared interests, games, conversation, and enjoying life together.

**Do we talk about VCFS during the peer groups?**

No. One of the things that makes these groups different is that **VCFS, medical diagnoses, and health problems are not the focus of our conversations.** This allows participants to take a break from thinking and talking about health-related issues and simply enjoy spending time with their peers.

**What do participants talk about?**

Almost anything that brings people joy! Topics can include hobbies, travel, food, movies, music, pets, sports, holidays, favorite activities, and other interests. The goal is to focus on the things participants enjoy.

**What kinds of activities do you do?**

We love to play games! Activities have included Hangman, Jeopardy, Kahoot, and other games that encourage participation, laughter, friendly competition, and mental stimulation.

**Is this a therapy or support group?**

No. The peer groups are **not therapy groups and are not intended to replace professional mental health or medical support.** Their purpose is social connection, friendship, recreation, and having fun with peers.

**Can participating in the peer groups help with anxiety or happiness?**

The groups are not designed as a treatment for anxiety or other mental health concerns. However, many participants and their families have reported that participants seem happier and experience less anxiety after becoming involved. These observations highlight the potential value of positive social experiences and meaningful peer connections.

**Why is it important not to focus on VCFS?**

For many people, living with a genetic condition means that health-related topics can occupy a significant amount of their lives. The peer groups offer something different: a place where participants can put those topics aside and simply be themselves.They can laugh, play, socialize, share their interests, and enjoy time with friends without having their diagnosis define the conversation.

**Who can participate?**

The peer groups are designed for individuals with VCFS who want an opportunity to socialize and connect with others that also have a VCFS diagnosis. Our participants are from all over the US and also some areas of Canada and we are working on establishing international peer groups as well. We ask that if you are not already registered with the Virtual Center for VCFS that you please do so in order to participate. There is no cost to you and you can register with the Virtual Center at https://www.vcfscenter.org There is no obligation to participate in any way with the professional staff of the Center, although they will be available to you if you would like.

**What if someone is shy or doesn't want to talk?**

That's okay! Participants can participate at whatever level feels comfortable for them. Games and activities provide natural opportunities to join in without having to carry a conversation. Sometimes simply being present and listening is a first step toward becoming more comfortable.

**What makes these groups so successful?**

At their core, the groups provide something that many people with VCFS may not have enough opportunities to experience: **regular time with peers where the goal is simply to have fun.** It gives them the ability to break their isolation and to introduce them to people who may end up being friends beyond the boundaries of the group. The combination of friendship, shared interests, laughter, games, and a positive environment creates a space where participants can look forward to seeing one another and enjoy being part of a community.

And perhaps that is the greatest success of all—not simply that our participants attend, but that **they look forward to coming back.**

**When do the peer groups meet?**

We currently have 4 times that peer groups meet:
Wednesday from 5-6pm EST
Thursday from 5-6pm EST

Friday from 4-5pm EST
Sunday from 4-5pm EST
However, as more people register with the program, new days and time will be added so that groups are kept at a size that encourages conversation with everyone in the group. If a group is too large, it may not give everyone an opportunity to participate sufficiently.

**How do I join?**
After you have registered with the Virtual Center (if you are not already a registrant), please contact our director of peer groups, Raymond Cheng at raymond.cheng@vcfscenter.org and he will schedule an introductory Zoom call with the participant and their families (if necessary). Ray will talk to you about the groups and find out a little about your interests, hobbies and get to know you a little bit.

**Is there a fee to join?**
The Virtual Center for VCFS never charges a penny for anything that we do for the VCFS community. We are able to provide expert information and support our peer groups thanks to the generosity of our donors that believe in the valuable work that we do.

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## A New Expert Has Joined Our Team
## George Cisneros, D.M.D.



Dr. George J. Cisneros is Professor of Orthodontics at New York University College of Dentistry. A recipient of the prestigious Milo Hellman Award from the American Association of Orthodontists (AAO), his main research interests include the evaluation of facial growth and development using nuclear medical imaging techniques, the diagnosis and treatment of patients with obstructive sleep apnea, the impact of fixed orthodontic appliance design upon the efficiency of tooth movement and the study of various computer-imaging technologies. Other research interests include the use of speech appliances in children with velopharyngeal insufficiency, the relationship between malocclusion and speech sound production, as well as patient self-image and perception of need for orthodontic care. He has published more than 30 original articles. He is a Diplomate of the American Board of Pediatric Dentistry and the American Board of Orthodontics, serving on both of their advisory committees. He also served on the Board of Trustees for the American Academy of Pediatric Dentistry. For nearly 20 years he served as the Dental Director of the Center for Craniofacial Disorders at Montefiore Medical Center and the Albert Einstein College of Medicine where he followed hundreds of cases of children with VCFS.

## ARTISTRY FROM OUR REGISTRANTS
**From our friends who have agreed to share their talents**

**Featuring the beautiful Gem Art of the talented Chesney Reynolds from Tennessee**





