



The Virtual Center for VCFS

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Issue 05

VCFS News: Your Information Resource

In this issue:

- Meet Ali Oppenheimer and Michael Landsman, two adults with VCFS who have made their mark on this world with some amazing accomplishments.
- Q&A with Ali Oppenheimer, a recently retired reading specialist in a highly regarded public school system in New York State.
- Michael Landsman, pursuing the highest ranks of expertise in the Korean martial art of Tae Quon Do.
- Photograph of the month: Happy birthday to the golden doodle named Graham.

ANNOUNCEMENTS

VCFS Peer Group Announcement!

Our Director of Peer Relations for the Virtual Center for VCFS, Raymond Cheng, is busy working on contacting everyone that has emailed us to say that they would like to participate. Thank you to those of you that have already contacted us, we are so excited to get the groups up and running! Just a reminder, if you or your children are interested in participating in the VCFS peer groups, please email Jodi Bloom via email at jodi.bloom@vcfscenter.org and include your name, address, email and phone number as well as hobbies and interests. We look forward to seeing you soon!

Free Book Offer To Our Registrants!!

The Virtual Center for VCFS would like to thank the generous donors that have offered to purchase 100 of Ali Oppenheimer's recently released book, "My Friends the Sun and the Moon" to give to the first 100 registrants that contact us! Please email Raymond Cheng, raymond.cheng@vcfscenter.org with your name, mailing address and phone number and a book will be mailed to you at no charge. Thank you to our generous donors!

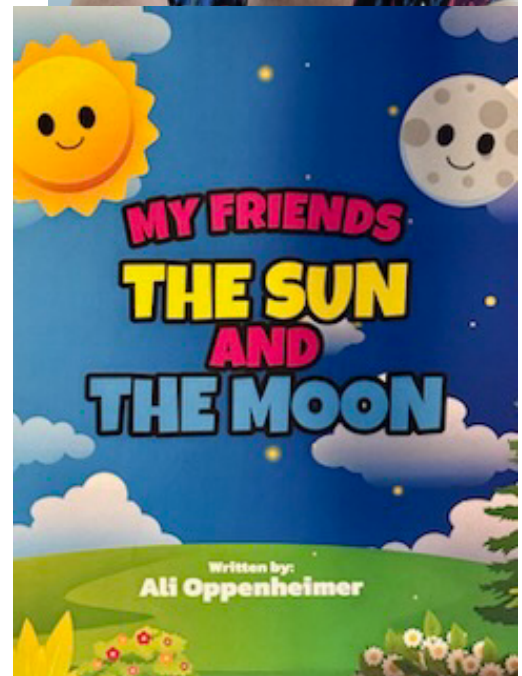
Ali Oppenheimer

Alexandra Oppenheimer, known always as Ali, as described by Dr. Shprintzen:

Ali has a wonderful story to tell. I first met Ali when she was a young four-year-old in the 1970s. Back then, I was relatively new to Montefiore Medical Center and the Albert Einstein College of Medicine in the Bronx. I developed a strong interest in the field of genetics. At that time, the study of people, especially children with congenital anomalies, was called teratology, which then changed to syndromology, then dysmorphology, and now broadly called clinical genetics, was in its infancy and people from many disciplines joined in. Ali entered the Center for Craniofacial Disorders at Montefiore after I became the Director of the program in 1974. We made the diagnosis of VCFS immediately. In our very busy Center, I was following a cohort of patients who had strikingly similar clinical profiles that included congenital heart disease, a typical (although not abnormal) facial appearance, learning disabilities, and severely hyernasal speech. In 1978, I published an article describing a “new syndrome” we called velo-cardio-facial syndrome in *The Cleft Palate Journal* together with some of my colleagues at Montefiore.

That paper became the most cited article ever published in the world’s academic literature related to craniofacial anomalies (based on a 2015 article published in *The Cleft Palate-Craniofacial Journal*). In the article I wrote, there were four pictures of cases with the syndrome shown to demonstrate the appearance of these children. Four facial pictures of the young girls with the syndrome were in the article. Only one face in the set of four was smiling...Ali’s. I am pretty sure that I have never seen Ali without a smile

on her face. When I see Ali...I smile. Her successes in life are remarkable. Her book, “My Friends, The Sun and the Moon” is a masterpiece of joy and compassionate feelings, and I would not have expected less from her. Our Editor, Raymond Cheng, posed the questions shown below to Ali who answered them without hesitation. Now retired after teaching in the New Rochelle, NY Public School System, Ali remains an active adult who loves travel, art, and cooking. I visited with her just two weeks ago, and her smile was still as prominent as ever.



Ali Oppenheimer bio (this is from Ali):

I have always loved books. My fondest childhood memories are of my mother reading bedtime stories. This inspired me to become a reading specialist. I wanted to give children the opportunity to fall in love with stories even if reading was difficult for them. I grew up with learning disabilities and had a challenging time learning how to read. I ended up teaching for over 20 years at a public elementary school in New York State. Due to the pandemic, I retired early, and I now pursue my dream of writing. I was happy to reply to Raymond Chengs excellent questions as shown below:

Q: What inspired you to become a reading specialist?

A: I had difficulty learning to read because of my learning disabilities. However, I have always loved stories and wanted kids who might also have difficulty learning how to read to love stories as much as I did when I was growing up.

Q: Did you hesitate at all to become a reading specialist because of any learning challenges you had as a child?

A: I did hesitate because it meant I had to go back to school. I wasn't sure if I'd be able to complete my master's degree. Now, in addition, I had to go get a reading license. However, I quickly realized how much it meant to me. Not only was it important to me to teach children how to read and write, but it was also important to me to believe in myself and know that there's nothing I can't do if I put my mind to it.

Q: What did you enjoy most about being a reading specialist?

A: I loved that, "Ah-ha" moment when the kids just "got it." I loved the pure joy and pride that showed on their faces! They were so excited! The hugs were great too!

Q: It is amazing that you wrote "*My Friends, the Sun and the Moon.*" What gave you the inspiration to write it?

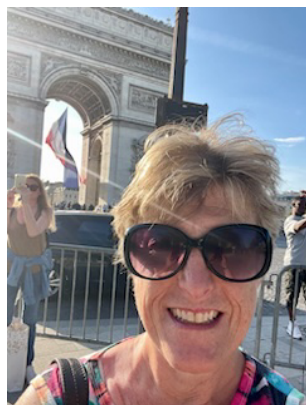
A: I've always wanted to write, and I've always loved the sun and the moon. Because of the work I was doing, this was kind of a natural progression!

Q: I understand that you enjoy cooking and we have seen you post many of your dishes on Facebook. What led you to cooking as a hobby and do you have a favorite style or type of cooking and why?

A: Basically, I love food! I like to prepare casual, easy, no-fuss food. One of the things I love about cooking is that if you make a mistake, it's not a big deal because it's just a meal and you can always try again.

Q: I know that you love to travel. What are some of the places you've been and do you have a bucket list of places you'd like to go?

A: I absolutely LOVE to travel! I love discovering new places and meeting new people. I've been all over Europe and to Africa, Morocco, Nicaragua, and I just came back from a trip to Guatemala! However, my favorite place to go is Paris and I'm even trying to learn French! It isn't easy but I love the challenge and I'm so proud of myself when I say something correctly. Australia and Greece are on my bucket list of places that I would love to go.



Ali in Guatemala (left) and in Paris, France in front of the Arc de Triomphe

Q: When you first started to travel, were you hesitant or frightened at all?

A: Yes, because of VCFS one of my disabilities is that I can get lost easily and I have a very poor sense of direction, so that definitely worried me. I am also a single woman traveling so that was always in my mind. I also used to be very disorganized so something like packing would cause a lot of anxiety for me. However, I did not let any of those reasons prevent me from the excitement of traveling to such wonderful places. Now, if I forget anything, it just gives me an excuse to shop!

Q: We are so excited that you will be involved with the peer groups (that our director of peer groups, Raymond Cheng, is very busy working to set up). What do you look forward to as we introduce this as a way for our registrants to connect with one another and make friends?

A: I'm looking forward to meeting new people from diverse backgrounds. I love that there will be opportunities for people to share experiences and come together to support one another. Also, let's face it... it's going to be fun!

Q: What role do you think your family played in your successes? Was there anything special you can point out that was helpful?

A: My parents never stopped believing in me and in the beginning, before we knew that I had VCFS, my mom never stopped trying to find an answer to the challenges I was facing. My parents knew how to motivate me without pushing me too far past my comfort zone. They never let me give up and they never gave up on me.

Q: Finally, do you have any advice for people with VCFS that are entering adulthood?

A: One point that I really want to stress is that you are not defined by the syndrome. You are you. Learn the most that you can about the syndrome and then take that knowledge and decide how you're going to use that information to help you live your best life. Oh, and remember to laugh! A lot! Laughter is still and always will be the best medicine.

Artwork and Pet of the Month

Hi! My name is Graham, and I am a golden doodle.

I love my friend, Jordyn, who tolerates my barking and makes nice parties for me. She is also a great artist and photographer 😊.

Photo courtesy of Jordyn Thornton



Michael Landsman, A Great Dad and A Teacher of Tae Quon Do

Michael Landsman, 39 years old, was diagnosed with VCFS at the age of 7 years. He has a wonderful nine-year-old daughter. He began studying the Korean martial art, Tae Quon Do, as a child and in October of 1998 he earned his 1st degree black belt and in April 2021 he earned his 4th degree black belt. He is currently studying for the Masters rank. Michael teaches Tae Quon Do part time to students ranging in age from four years to adulthood. He first studied martial arts in 1996 and both he and his parents claim it has helped him with anxiety and confidence, focus, and social skills. The reward of advancing successfully through the belts from white to black has taught him how hard work can lead to achieving goals that have helped him throughout life.



Teaching Tae Quon Do has been another challenge and rewarding in a different way as he watches the student's progress succeed under his tutelage. Michael shares parenting of his daughter, a very important part of his life. She does not have VCFS, but Michael believes any sort of parenting is difficult and filled with all sorts of challenges. He believes if you try to stay positive and have a strong connection with your child, you will have a great relationship. Michael, who has a job that keeps him busy also plays drums and bass guitar in local bands in the Madison, Wisconsin area.

What is a syndrome, and what is not?

Robert J. Shprintzen, Ph.D.
Director and President

The Virtual Center for Velo-Cardio-Facial Syndrome, Inc.

The word “syndrome” appears in our conversation fairly often. There is velo-cardio-facial syndrome and thousands of other medical conditions that carry a name that has “syndrome” in it. The word has also crept into the common vernacular, such as “Stockholm syndrome” or “brain fog syndrome” to indicate a set of circumstances or events that have multiple aspects that create a package of sorts. The word “syndrome” has been used in medicine quite often, but not all of those uses actually fit the conditions they describe. I’ll explain in the following paragraphs.

My interest in genetics started when I was in my senior year of college at the University of Rochester when I took a course in genetics. This was in 1968 when our knowledge of genetics was really on the ground floor, if not the basement. Most of our work in the labs were with tiny fruit flies, *Drosophila melanogaster*. This annoying little fruit fly was studied for genetic traits because they reproduced quickly with many offspring, have a two-week life span, only have four

pairs of chromosomes, have many of the same genes that humans have and take up very little space in the lab. At that time, we knew very little about the complexities of chromosomes and genes, how they worked and how they mutated. Nobody had ever heard the term microdeletion or deletion syndrome. In fact, we weren't even really sure how many chromosomes humans had until 1955. I loved the science of genetics but I wasn't crazy about *Drosophila* flying up my nose and getting in my eyes, so I focused more on clinically defined human disorders.

Then the science of "syndromology" came along in an era I consider to be a renaissance in the field of genetics from the mid-1970s through the early 1980s before molecular genetics began to accelerate. This is the time when scientists defined "syndrome." Today, with so many molecular genetic tests available, it is possible to be very specific about how the genetic diagnosis determines clinical consistency in syndromic diseases.

At that time, an international working group defined a syndrome as "the presence of multiple anomalies in the same individual with all of those anomalies having a single cause." In the case of VCFS, the common cause is the deletion of genes from a specific region within a specific portion of chromosome 22. Any anomaly that occurs with a different cause is not a feature of the syndrome. Why is this precise definition important? Because many of the successful treatments applied to VCFS are specific to the syndrome. This is true for surgical correction of hypernasality, pharmaceutical management of psychiatric illness, and even educational approaches to learning disabilities. There are disorders that often occur together with frequency, but they may not be a syndrome because they have many different causes. A good example of this is something called Robin sequence. Originally called "Pierre Robin syndrome" named after the French physician who first described babies with small lower jaws, cleft palate, and upper airway obstruction. However, many different things cause a small lower jaw, cleft palate has many causes, and the airway obstruction is usually related to the small lower jaw that causes the tongue to block the airway.

So, VCFS is a true syndrome. There is only one cause for it, and therefore when specific treatments have been shown to be effective, it is likely that they will work for almost everyone with the "syndrome." When a grouping of symptoms that do not have the same cause are treated, they will not all respond to the same treatment.



The Virtual Center for VCFS