

# THE RC SELPA COMMUNITY ADVISORY COMMITTEE

## Newsletter



### *Celebrating Families and Siblings Event*

On April 1, 2023 the RC SELPA Community Advisory Committee held a family event titled, "Celebrating Families and Siblings of Students with Disabilities." This free event allowed families to come together to learn more about how to support those family members with disabilities. The Riverside County SELPA Mental Health team held small group sessions, one for parents, and one for siblings, while students with disabilities engaged in a variety of sensory activities with our CAC members and volunteers. During the breakout sessions students engaged in hands on activities around identifying feelings and how to help others when they are struggling with their own feelings. Parents engaged in self care routines as well as how different children respond differently.

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### *CAC President's Message*

Hello CAC Members and Riverside County SELPA Community! My name is Vicky Iqueda, your CAC President. As we approach the end of the 2023 school year I want to take a moment to share how grateful and honored I have been to serve as your CAC President this year. At the CAC we are blessed to have a strong Executive Board willing to serve and a dedicated SELPA team ready to support us in all activities and meetings planned. This year we transitioned from virtual back to in-person meetings and workshops. The CAC Exec Board started our year with a very positive summer planning meeting where we determined the topics our community was interested in. We started the year with a "Donuts with Directors" event that was a success. We presented an IEP toolkit for families, and had a Transitional presentation on our students' options for life after high school. We had an informative attorney presentation on special needs trusts planning and conservatorship. We also presented on how to keep our Students Socialized after COVID and beyond. The CAC participated in an amazing Lego / E-sports event with RCOE and planned a Family / Sibling Workshop day with Mini Golf Fun!

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## LEGO Fun Fair

The Riverside County Office of Education and the Riverside County SELPA with the support of the Community Advisory Committee put together a LEGO Funfair. This opportunity was put together due to the efforts of many department across Riverside County collaborating in honor of creating more inclusive opportunities for students with disabilities.

Executive Director of Special Education at RCOE, Barbara Sorter, received a large donation of Legos, she used this donation to create the LEGO Funfair in partnership with the RCOE E-Sports, RC SELPA CAC, and the Santa Claus inc.

Families were able to come and see their student with disabilities engage with high school mentors on completing a LEGO set. Then, students were given the opportunity to engage in some e-sports activities. This opportunity allowed students to create a sense of belonging, boost self-confidence. This event was held again in the Spring in the Desert region so that our large county could have an opportunity to engage in this event as well. It was a huge success.



***"I love seeing my child be included and engaging with typical peers that they may not have had the opportunity to otherwise."***



## Student Spotlight

This student spotlight comes from Santa Rosa Academy, a charter school located in Menifee, CA. Jaela Hernandez is a 9th grade student and has Mucopolysaccharidosis which is a rare genetic disease. Despite this, she fully participates in everything at school and brings much joy to everyone she meets. She loves music and signing and would love to be a performer one day.

MPS is short for Mucopolysaccharidosis, a rare genetic disease that affects 1 in 100,000 live births. This disease doesn't allow her body to produce enough enzymes to properly break down sugar molecules that are found throughout her body which leads to numerous health problems.

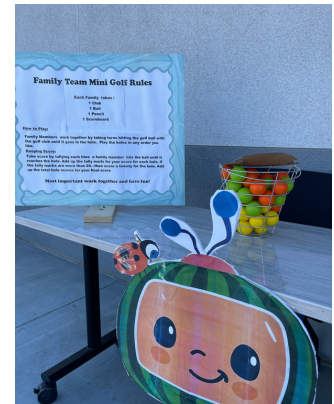
Like Jaela, most individuals impacted by MPS appear to be healthy at birth and experience a short period of normal development, followed by a decline in physical and or mental function. As the condition progresses, it may affect appearance, physical abilities, and organ function including the heart, joints, respiratory and nervous system. Fortunately for Jaela, she was diagnosed at a very young age, allowing her to start treatments right away.

Jaela underwent Chemotherapy, had a bone marrow transplant, and had ERT (Enzyme Replacement Therapy) which she will continue for the remainder of her life. ERT replenishes her body with the enzymes that her body cannot naturally produce. Jaela has had several surgeries and will continue throughout her life.

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## Celebrating Families (cont.)

It was special to not only see parents support other parents, but being surrounded by those that understand the unique circumstance that each of them work with each day. The day concluded with families having the opportunity to work together in a family team mini gold course that was custom made by our Member at Large, Cindy Lees', husband. These mini golf holes were accessible by any and all students regardless of need or disability. Families loved this opportunity to work together and most importantly have fun together. Thank you to the CAC and RC SELPA staff for making this event happen.



## President's Message (cont.)

To close out the year we had a parent from the CAC and her children in special education join our SELPA Director in Sacramento to meet our Legislators and present our community needs. We also ended our year with our 15th Annual CAC Recognition Event. We gathered as a SELPA with all 26 of our school districts and celebrated those community members that go above and beyond on a daily basis with our students in Special Education. It was a night full of emotions and fun all because of our Special Needs Community. This year was a success and it is contributed to the team work and the committed individual on this years CAC Executive Board members, the CAC members and our SELPA team. I am honored to have been part of this team and work alongside such amazing individuals.

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## District Spotlight-Coachella Valley USD

On March 25, 2023, Coachella Valley USD, Special Education Department held their Inaugural Ability Sports Festival. This event was inspired by a TikTok video that was seen by a special education teacher, Mrs. Michelle Ramos. She proposed the idea and likeness to her co-facilitator, Special education teacher Kim Lopez. Together they were able to create an amazing fun and inclusive event for the entire community. This was a big task and they were able to collaborate with the athletics department, special education department and community organizations. "Kim and I had the vision to create this fun little event to allow our students the opportunity to play sports alongside their peers. And see how anything is possible, if we just think outside the box. It turned out amazing and we can't wait for it to be bigger and better next year! We want more students to have this experience," Mrs. Ramos.



***"As a parent with a special needs child, this day was extremely important and much needed. I could not stop smiling to see the hundreds of students spread across the entire campus of Coachella Valley High School. I can only speak for myself, but I left that afternoon with my love tank full and filled with hope for my son and my family,"***  
***Yadira, Ezekiel's Mom.***

The event consisted of adaptive sports, arts and crafts, raffles, games, sensory stations and a resource fair. Adaptive sports included wheelchair basketball, baseball, football, soccer, tennis, golf and much more. Kelsey's Heroes, a local baseball team for individuals with disabilities play a game with the CV Arabs. Both team were mixed and all the athletes enjoyed sharing the dugout and field together as they cheered for one another.

As students engaged in sports, parents, caregivers, and community members were able to visit the resource fair. Resources ranged in the area of educational, sports, and health. Some organizations in attendance were: Ezekiel's Gift Of Love Coachella Valley Down Syndrome Foundation, GANAS, We Can Fish, United Cerebral Palsy of the Inland Empire, Desert Recreation District, CV Arabs football and SoCal Adaptive Sports. This is the first event that highlighted adaptive sports to include all members at CVUSD and hopefully the first of many to come.

## *Student Spotlight (cont.)*

As you can imagine, this is devastating, yet Jaela is so optimistic and doesn't let anything get her down. Jaela loves to dance and sing like no one is watching! Her laughter is contagious, and she is just a joy to be around. There is currently no cure for this terminal disease, however there are treatments and therapies that can help those affected by MPS/ML live a bit more comfortably. With your help we can continue to fund research to find a cure for MPS/ML. The National MPS Society is a non-profit organization dedicated to improving the lives of children and families who are impacted by these genetic diseases and to help fund research for a cure. Please visit their website for more information.  
<https://mpssociety.org/>



## *Presidents Message (Cont.)*

We don't stop here. We have much more work that needs to be done. At the CAC we look forward to gathering again at our Summer Planning meeting and begin planning next years presentation, events and workshops. We look forward to serving our Special Needs community with more diligence and commitment than this past year. We, the CAC Executive Board, truly want to make a difference in our Special Needs community. If you want to make a difference let us come and work together to improve the access and services for all students in our districts across Riverside County SELPA. Thank you all for the opportunity to serve and thank you all that served this 2022-2023 scholar year. I appreciate you all.  
 Sincerely,  
 Vicky Iqueda, your CAC President